

Type 1 Diabetes in Men:  
A Grounded Theory Exploration of Life with a Chronic Illness

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## Abstract

**Objectives.** The objective of this study was to gain an understanding of men's *holistic* experience of life with Type 1 diabetes.

**Design.** One-to-one interviews were conducted with 15 men, all of whom have Type 1 diabetes. Interviews were also conducted with 10 diabetic men and their partners. All interviews were audio-recorded and subsequently transcribed. Additionally, postings to an online-forum, specifically dedicated to men with diabetes, were collected. All data were analysed using a grounded theory style approach. This involved developing codes and abstract categories from the data which, when linked together, provide an understanding of men's experience of life with diabetes.

**Results.** The relationship between men and diabetes is established in response to the perceived congruency between the management of diabetes and the attainment of personal goals. This relationship is not fixed, rather as personal goals shift (in response to changing personal circumstances) so too do one's relationship with diabetes. The centrality of the couple to the experience of life with diabetes is evidenced in the way men and their partners respond to the presence of diabetes-related erectile dysfunction, and also in the way they negotiate the daily management of diabetes, through varying levels of reliance.

**Conclusions.** The results point to the all-encompassing nature of diabetes and highlight the need for research to move its focus from issues of self-management to the *holistic* experience of living with Type 1 diabetes. While men pursue the fulfilment of personal goals, over the health-related goals of diabetes, they are unable to fully escape the hold of diabetes. It is the psychological weight of living with diabetes which negates normality. It is important therefore, for this aspect of diabetic-life to be acknowledged and attended to if the quality of life of those affected by diabetes is to be maximised.

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## **Ch. I Introduction**

### **1.0**

The present study explores the experience of living with Type 1 diabetes, as informed by a group of men with the disease. In this chapter, I shall provide a brief insight into the origins of this research, which reside in my own experience of living with diabetes. Section 1.1 details how my personal interest in diabetes came about. In Section 1.2 I discuss how the goal of the research was established. Finally, in Section 1.3, I detail the structure of this thesis.

### **1.1 Personal background to research**

I was diagnosed with Type 1 diabetes in August 2006. The diagnosis came eight weeks after my youngest sister was diagnosed with cancer and two weeks before I was due to move to the UK to commence my Masters in psychology at Nottingham Trent University. Despite knowing remarkably little about the disease, both my reaction and the reaction of my family to my diagnosis was generally one of relief that 'it was only diabetes'. To be told that I needed to follow a strict diet and inject myself with insulin seemed relatively easy when compared to the gruelling chemotherapy my sister was enduring. Indeed for the first number of months, I blindly adhered to every health-recommendation on a day-to-day basis and focused the rest of my energy on my move to the UK and on my sister's recovery. Her remission from cancer in November of that year was the first point at which I contemplated the longevity of my disease and the fact that there would be no recovery. In my experience, this is the most difficult aspect of living with Type 1 diabetes. I do not suffer from it, I am not ill with it but I am frustrated by the fact that I will live with it for the rest of my life. Around that time I started researching psychological studies which examined this aspect of diabetic life. I was surprised to find very few studies which looked at 'patients' reactions to the chronicity of the disease. Rather, research into Type 1 was dominated by quantitative studies examining issues surrounding the adherence to the recommended diabetes regimen and the attainment of optimum blood-glucose levels. I felt that these were issues which reflected the concerns of health professionals but did not attend to my

concerns as someone living with the disease. This led me to carry out my own research into the experience of life with Type 1 diabetes as my Masters dissertation. This research, which has since been reworked and published (see Watts, O'Hara, Trigg, 2010)

I feel that it is important to share my background information with you, the reader, so you can understand the personal biases that I, as a diabetic researcher, bring to the research process. Before agreeing to take part in the research, I informed all participants that I too had Type 1 diabetes. At times during interviews I shared my participants frustrations at the quality of healthcare they were receiving, I joined with them in discussions of potential cures and advancements in treatments and, when asked, I shared with them details of my own treatment regimen.

## **1.2 Establishing the goal of the research project**

When first invited to apply for a PhD research position in the area of men's health, my thoughts quickly turned to how diabetic men experience life with erectile-dysfunction (ED) (a complication which affects almost one third of men with diabetes). The presence of ED as a complication is the 'obvious' element which separates the experience of diabetes for men and women. While, this research proposal was approved, after greater consideration I felt that I was turning my back on what was most important to me as someone with diabetes, that is, research which takes into account the *holistic* experience of living with diabetes. It was not my position to dictate that the presence of ED is a significant part of diabetic-life for all men with the disease and therefore worthy of PhD research. Rather, I needed to allow men with diabetes the opportunity to make their experiences relevant, rather than direct the research in a specifically gendered way. My goal was not to highlight the differences (if any) between men and women, but rather focus on men's experience of illness in its own right.

## **1.3 Structure of Thesis**

This thesis begins by offering a review of the literature relevant to the research area covered in this study. To this end, Chapter II begins by situating the research within

the field of critical health psychology. Following that, background information regarding the nature of diabetes as a disease is offered, before addressing the existing qualitative and quantitative literature which into diabetes. I then review research which has looked at gender and diabetes, in an attempt to gain an understanding of what we already know about how men experience life with this disease. Following that, research into men's health is considered, with specific attention given to literature addressing the interaction between masculine identity and engagement in health-related behaviours. Finally, the familial experience of illness is considered.

The methodology employed in this thesis is detailed in Chapter III. Here, an introduction to the grounded theory (GT) approach (and its proponents) is offered before detailing the specific approach used in this research.

Chapters IV, V, and VI represent the empirical research chapters of this thesis. Chapter IV is concerned with men's experience of life with Type 1 diabetes. Based on one-to-one interviews with fifteen diabetic men, this study attends to their *holistic* experience of living with diabetes. The findings suggest a process of adjustment to diabetes, in which the pursuit of personal goals informs the extent to which the diabetes-regimen will be incorporated into daily life.

Chapter V is concerned with the issues made relevant by men in an online forum, specifically dedicated to men with diabetes. In this case, the experience of erectile dysfunction is discussed openly by users of the forum, and the centrality of the couple to the experience of ED is highlighted.

Chapter VI follows on from the centrality of the couple highlighted in Chapter V, to illustrate how couples experience life with Type 1 diabetes. Here, the separation of diabetes into two distinct spheres is presented as the means through which couples preserve the *normality* of their lives.

Finally, in Chapter VII, I discuss the main findings of the research and how they contribute to what we already know about men's experience of Type 1 diabetes. The limitations and practical implications of the research are also presented.

## Ch. II Literature Review

### 2.0 Introduction

The present study aimed to gain an understanding of men's experience of life with Type 1 diabetes. While diabetes is extensively researched within the field of health psychology, the focus of such research is overwhelmingly directed towards the self-management of the disease to the neglect of the *lived experience* of those affected by it. Additionally, despite a surge of interest into men's health in recent years, very little is known about how men experience life with a chronic illness such as diabetes. Indeed, Leonard (2004) argues, mens' perspectives of diabetes-related health issues 'have been either inadequately investigated or not investigated at all' (p.206). In the following chapter, the fields of literature relevant to the research area of this thesis are discussed. I begin by locating the research in the field of critical health psychology. A background to diabetes is provided in section 2.2 before the qualitative and quantitative research into Type 1 diabetes and Type 2 diabetes is discussed. Following that, the literature relating to children and adolescents with diabetes is briefly considered in section 2.3 before a review of research into gender and diabetes in 2.4. Men's health literature is reviewed in section 2.5. The familial experience of life with a chronic illness is considered in section 2.6. A brief summary of the literature review is presented in section 2.7, and the aims of the research are detailed in section 2.8.

### 2.1 Locating the Research in a Field of Health Psychologies

#### 2.1.1 Biomedical model of illness

*'In this model, a symptom of illness is considered to have an underlying pathology that will hopefully, but not inevitably, be cured through medical intervention. Adhering rigidly to the biomedical model would lead to proponents dealing with objective facts and assuming a direct causal relationship between illness, its symptoms or underlying pathology, and adjustment outcomes'.*  
(Morrison, V. & Bennett, P., 2006., p. 29)

This account of the biomedical model of illness has been translated into a field of biomedical research which is concerned with ‘bringing together fundamental and applied aspects of biology and medicine with the ultimate aim of contributing to the improvement of human health, e.g. by searching for causes and working mechanisms of, and/or therapies for, pathological disorders’ (Caron-Flinterman, Broerse, & Bunders, 2005, p. 2576). While more recently, there has been a call to integrate the *experiential* knowledge of patients into such research (Caron-Flinterman et al. 2005), the field is preoccupied with the causation of illness and the effect of treatment at the molecular level.

Looking specifically at recent biomedical research into diabetes, studies are marked by an absence of human participation. Mouse models have been utilised in studies examining the biological mechanisms which underlie a diagnosis of Type 1 diabetes (Holmes & Cooke, 2012), the pathogenic mechanisms which are employed in the destruction of beta-cells (Graham et al. 2012), explorations of the genetics involved in the causation of Type 1 diabetes (Driver, Chen, & Mathews, 2012) while the ‘selective damping’ of damaging autoimmune responses resulted in permanent remission from diabetes for mice in a study conducted by Chatenoud (2010). Using human participants, biomedical research in diabetes has also looked at immune-directed therapy for people with Type 1 diabetes (Ehlers & Nepom, 2012) and the efficacy and challenges of islet cell transplantation (Shapiro, 2012). In these cases, the human participant represents a measurable subject, which when exposed to appropriate testing will inform advancements in the treatment (and potential prevention or cure) of Type 1 diabetes.

As stated, there has been a call to supplement these scientific explorations by acknowledging, and inviting, the experiential expertise of those living with chronic illness to contribute to this field of research. Caron-Flinterman et al. (2005) argues that ‘biomedical knowledge concerns external objects and is mainly acquired through detached and impersonal study and observation, while patients’ experiential knowledge concerns the personal situation and is acquired through personal and bodily experiences. In this sense, the experiential knowledge of patients can be said to complement the biomedical knowledge of professionals’ (p. 2577). Indeed,

participants in their study referred to biomedical research as only relevant from a scientific perspective but not from a patient perspective. Thus, the inclusion of patients as contributors and collaborators in this field of research may result in the broadening of the scope of such research to attend to issues of both scientific and personal relevance.

### 2.1.2 Mainstream Health Psychology (MHP)

Taylor (1995) defines health psychology as ‘the field within psychology devoted to understanding psychological influences on how people stay healthy, why they become ill, and how they respond when they do get ill. Health psychologists both study such issues and promote interventions to help people stay well or get over illness (Taylor, 1995, p. 3, cited in Prilleltensky, 2003)’. Mainstream health psychology shares a similar emphasis on scientific method as that endorsed by the biomedical research and has received criticism for its positivistic foundations (Stainton Rogers, 1996). Borne out of such positivism are the concepts of *compliance* and *adherence* which have become synonymous with MHP investigation into chronic illness.

Despite being introduced into medicine, by Sackett, in 1976, there is no agreement regarding the definition of *compliance* (Kungäs, Duffy & Kroll, 2000). However, it is generally accepted to mean the extent to which an individual’s behaviour coincides with the medical advice he/she has received (Kungäs et al., 2000). This advice may refer to medication usage and/or life-style changes. Inherent in this notion of compliance, is an image of the healthcare professional as the authoritative figure who possesses absolute knowledge about health, and power over the healthcare scenario. The individual affected by illness is judged against the health-professional’s recommendations and labelled as either ‘compliant’ or ‘non-compliant’, with ‘non-compliant’ resulting in a moral label of ‘bad’ or ‘difficult’ patient (Lutfey & Wishner, 1999). In their conceptual analysis of the term, Kungäs et al. (2000) attended to the identification of ‘compliance’ as an ideology. With reference to the work of Playle and Keeley (1998) they state ‘[t]he ideological assumptions connected to the term compliance underpin the maintenance of professional power and control...This ideology is based on assumptions that patients

have a passive role in their health care and are passive recipients of treatment' (p. 7).

Akin to paternalism, the lack of autonomy afforded to 'patients' has been one of the main criticisms of the use of the term 'compliance' in MHP. As Luftey and Wishner (1999) conclude, '[u]nder the 'compliance model, patients are saddled with complex daily responsibilities for their own medical care, yet they surrender most decision-making and control to medical practitioners' (p. 637). A further note of caution is raised regarding the difficulty in measuring compliance, or 'noncompliance', as the recommended treatment of chronic illnesses often include multiple levels of intervention including drug-treatment, and adjustments to diet and exercise regimes. Thus, to measure compliance one must assess each area of treatment, develop an accurate account of patients' engagement with each measure and assess this engagement against the detailed recommendation of health professionals.

A move towards use of the term *adherence* (instead of compliance) represented an attempt to acknowledge patients' active participation in their own health care, and minimize the authoritative role of the health care practitioner. The distinction between *compliance* and *adherence* (as proposed by the World Health Organisation, 2003) is that 'adherence implies that the patient agrees with the prescribed recommendations rather than passively obeying' (Bissonnette, 2008, p. 637). Despite this differentiation, a concept analysis of the term 'adherence' found no real distinction in its usage to that of 'compliance' and both terms appear to be used interchangeably (Bissonnette, 2008). Similar to 'compliance', no official definition of 'adherence' was located, while the most common definition followed that of Haynes et al. (2005): 'the extent to which patients follow the instructions they are given for prescribed treatments' (Bissonnette, 2008, p. 636). I would argue that this definition does little to contain the power afforded to healthcare professionals and thus offers no real improvement on the term 'compliance'. The health professional is still equipped with the power to instruct, and the patient is judged by the level of their obedience to such instruction. Efforts were made to introduce *concordance*, as an alternative concept of adherence, which implies 'the development of an alliance between patients and healthcare providers based on realistic expectations as opposed to misunderstanding, distrust and concealment' (Bissonnette, 2008, p. 637), however usage of this term has not been successfully established in MHP.



### *2.1.3 Mainstream Health Psychology and Diabetes*

The concepts of compliance and adherence have become the foci of mainstream health psychology research into diabetes. In the context of chronic illness more generally, Haynes et al. (2005) report an average adherence rate of 50% and range from 0% to 100%. MHP research show rates of adherence for people with diabetes varying from 20% to 80%. The variation is dependent upon the component of the regimen. Peyrot et al. (2005) noted self-reported adherence rates for medication, blood glucose monitoring, diet and exercise as 83%, 70%, 39% and 37% respectively. These results illustrate the difficulties in providing an overall measure of adherence in terms of diabetes, as to do so belie the complexities of diabetes-management. Indeed, Bennett Johnson (1992) explored the methodological issues in measuring adherence amongst people with diabetes. She argued ‘the absence of explicit adherence standards against which the patient’s behaviour can be compared; inadvertent noncompliance attributable to patient-provider miscommunication and patient knowledge/skill deficits; the behavioural complexity of the diabetes regimen; and the confounding of compliance with diabetes control’ act as conceptual problems when defining and measuring adherence (p. 1658).

In order to understand variation in adherence rates among people with diabetes, researchers have explored the factors that influence adherence. For example, Delamater et al. (2001) identified demographics (ethnicity, socioeconomic status and education) as having an impact on levels of adherence, while other researchers have pointed to the impact of social factors (Griffith, Field, & Lustman, 1990) and healthcare provider factors (Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992) on adherence levels. Additionally, Ciechanowski, Katon, and Russo (2000) have reported on the negative impact psychological problems may have on regimen adherence. This interaction is particularly important to note given that between 65% and 70% of people with Type 1 diabetes experience psychological problems (McGuire & Walsh, 2006).

As will be demonstrated later in this chapter, there appears to be a preoccupation amongst diabetes researchers with the ‘self-management’ of diabetes, in which

adherence to the diabetes regimen occupies a pivotal role. I argue that such an approach has resulted in a compartmentalized examination of life with diabetes in which a focus is placed on the interaction between individual factors and the success of self-management behaviours (as measured via blood-glucose levels). There is an inherent failure in this research to observe the individual with diabetes as an autonomous entity, whose self-management of their disease is informed by their own unique demographic, social, cultural, and environmental make-up. Rather, mainstream health psychology research into diabetes has been marked by a reductionist approach.

#### *2.1.4 Adopting a critical health psychology stance*

*‘Stam (2000) questions mainstream health psychology’s non-critical and nonreflexive definition of health and illness. So long as we define health as simply regaining the ability to perform, and adopt a likewise uncritical stance towards such constructs as ‘adjustment’ and ‘quality of life’, ‘we deny that we are collectively, as a profession, defining a set of outcomes for others’ (2000, p. 279). Only by negotiating the meaning of such constructs with affected individuals, can we hope to create research and practice that is relevant, effective and empowering’ (In Prilleltensky, 2003, p. 200).*

As my aim was to gain a *holistic* understanding of what life is like for men with Type 1 diabetes, I position my research in the field of critical health psychology. I wanted to involve ‘affected individuals’ in my research and as such, provide a representation of their experiences of life with Type 1 diabetes. As will be demonstrated in the remainder of this chapter, there is a paucity of holistic accounts of diabetic life in the literature. Rather, the mainstream health psychology concern with the interaction between specific units and self-management of diabetes dominates.

## 2.2 Diabetes

Diabetes affects approximately 2.8 million people in the UK and there are approximately another 850,000 people who have the disease but have yet to be diagnosed ([www.diabetes.org.uk](http://www.diabetes.org.uk)). Two main types of diabetes exist: Type 1 diabetes and Type 2 diabetes.

### 2.2.1 Type 1 Diabetes

Type 1 diabetes is an autoimmune disease which occurs when the body kills off the insulin-producing cells of the pancreas. It accounts for approximately 5% of all diagnosed cases of diabetes ([www.cdc.gov](http://www.cdc.gov)). The onset of Type 1 diabetes has been attributed to genetic susceptibility and environmental factors. While susceptibility to Type 1 diabetes is an inheritable trait (concerning specific human leukocyte antigens), more than 85% of diagnoses occur in the absence of an affected first-degree relative (Gan, Albanese-O'Neill, & Haller, 2012). A vast list of factors have been examined in the hopes of identifying the environmental trigger concerned in the onset of Type 1 diabetes. Specifically, diet, cow's milk, protein exposure, vitamin D deficiency, viral infections, drugs, toxins and stress have all been implicated as triggers but to date, 'no one specific environmental trigger has been found to clearly and definitively cause' Type 1 diabetes (Gan et al., 2012, p. 273).

The management of Type 1 diabetes relies on the artificial administration of insulin, either through multiple daily injections or continuous subcutaneous insulin infusion also known as insulin pump therapy (at present, approximately 6% of people with Type 1 diabetes in the UK have an insulin pump ([www.diabetes.co.uk](http://www.diabetes.co.uk))). In addition to the administration of insulin through these means, self-monitoring of blood-glucose levels should be performed at least four times per day (Gan et al., 2012), and a healthy balanced diet complimented by regular exercise ([www.diabetes.org.uk](http://www.diabetes.org.uk)) should be adopted. The goal of this regimen is to achieve an optimal HbA1c level (the amount of glycated hemoglobin in the blood) which, it is hoped, will minimise and delay the potential onset of diabetes-related complications (for example, retinopathy, neuropathy and heart disease) (Diabetes UK, 2008). People with Type 1 diabetes (and their carers) must also be alert to the signs and symptoms of

hypoglycaemia (low blood-glucose levels). These symptoms may include ‘dizziness, shakiness, sweating, personality changes, irritability, anxiety, changes in vision, weakness, headache, inability to concentrate, tachycardia or palpitations’ (Gan et al., 2012). Such hypoglycaemic episodes require immediate treatment with 15g of fast-acting carbohydrate. If left untreated, hypoglycaemia can be fatal. Recent figures show that fatalities attributed to nocturnal episodes of hypoglycaemia (referred to as ‘The Dead in the Bed Syndrome’) represent 6% of all deaths of people under 40 years of age with Type 1 diabetes ([www.diabetes.co.uk](http://www.diabetes.co.uk)).

### *2.2.2 Type 2 Diabetes*

While Type 1 diabetes is an autoimmune disease, Type 2 diabetes by contrast, is caused when the body is unable to effectively use the insulin being produced, or is not able to produce sufficient insulin for the individual's diet. Type 2 diabetes accounts for 90% of people with diabetes around the world (World Health Organisation, 2013). A number of factors can increase the risk of developing Type 2 diabetes. These include: being overweight; having a close family member with Type 2 diabetes; having high blood pressure; and having high cholesterol ([www.diabetes.co.uk](http://www.diabetes.co.uk)). Indeed, Type 2 diabetes can potentially be avoided by maintaining a healthy diet and active lifestyle ([www.diabetes.co.uk](http://www.diabetes.co.uk)). Type 2 diabetes is managed in a similar way to Type 1 with an emphasis placed on diet modification, engagement in exercise, and blood-glucose monitoring. However, for most people with Type 2 diabetes, insulin injections are not required immediately and oral medication, or even changes to diet alone, can suffice in the treatment of the disease.

### *2.2.3 Diabetes-related complications*

The elevated blood-glucose levels caused by diabetes impacts on the entire body, and thus results in several potential diabetes-related complications. In particular, diabetes can damage the heart, blood vessels, eyes, kidneys and nerves. Referring to the National Diabetes Fact Sheet (2011), (produced by the Centers for Disease Control and Prevention ([www.cdc.gov](http://www.cdc.gov))) and The World Health Organization Fact Sheet No. 312 (2013), below are statistics regarding the prevalence of diabetes-related complications:

- ‘50% of people with diabetes die of cardiovascular disease’ (WHO, 2013)
- ‘Diabetes is the leading cause of new cases of blindness among adults aged 20-74 years’ ([www.cdc.gov](http://www.cdc.gov))
- ‘Diabetes is the leading cause of kidney failure, accounting for 44% of all new cases of kidney failure in 2008’ ([www.cdc.gov](http://www.cdc.gov))
- ‘Combined with reduced blood flow, neuropathy (nerve damage) in the feet increases the chance of foot ulcers, infection and eventual need for limb amputation’ (WHO, 2013)
- ‘More than 60% of nontraumatic lower-limb amputations occur in people with diabetes’ ([www.cdc.gov](http://www.cdc.gov))
- ‘About one-third of people with diabetes have severe periodontal disease consisting of loss of attachment (5 millimeters or more) of the gums to the teeth’ ([www.cdc.gov](http://www.cdc.gov)).
- ‘People with diabetes are twice as likely to have depression as people without diabetes in the same age group’ ([www.cdc.gov](http://www.cdc.gov)).

This is by no means an exhaustive list of complications. Rather, it serves to give an insight into the potential side-effects of diabetes and also provides a context from which the research which has focused on the improvement of self-management of diabetes (with the hopes of preventing such complications) can be viewed. Such research will be considered in the following sections.

#### *2.2.4 Qualitative research into Type 1 diabetes*

The body of qualitative literature into Type 1 diabetes can be divided into research focused on living with the disease, and research concerned with self-management of diabetes.

In the case of the former, the ever-evolving way in which one lives with diabetes has been evidenced by a number of researchers who highlight how living with the disease raises issues regarding control and identity; and leads to the pursuit of balance, stability and normality which are achieved through processes of

'transformation' and 'redefinition'. Highlighting the individual variability in the experience of living with Type 1 diabetes, Watts, O'Hara and Trigg (2010) refer to the significance of the relationship between the personally-held goals of the individual and diabetes-enforced goals. Their by-case analysis illustrates the potential for psychological conflict, as individuals are forced to contemplate the trade-off between these two elements. The authors conclude that the satisfaction of both sets of goals (personal and health) need to be attended to if psychological and physical quality of life is to be maximised.

Hernandez (1996) describes an ongoing process of integration of personal and diabetic selves. Individuals with diabetes progress from the 'having diabetes' stage marked by minimal knowledge of and attention to diabetes, with resulting poor glycemic control, to the ultimate 'science of one' stage in which a deep understanding of, and sensitivity to, one's *own* diabetes is developed. Here diabetes is integrated into life but does not dictate how life should be lived. The individual with diabetes progresses to this stage of integration from the 'having diabetes' phase via 'the turning point' where the person with diabetes is forced to give the disease, and how they live with it, their attention.

The emphasis on the individual in Hernandez's (1996) work can also be seen in Paterson, Thorne, Crawford and Tarko (1999) process of personal transformation in which 'the individual learns to restructure the self and the illness experience through the differentiation of the self' (p. 799). In this case, participants learned to live with diabetes through a process of discovery in which they became aware of their ability to control diabetes, rather than be controlled by it. This discovery gave rise to a sense of self that is separate from illness and capable of dealing with the challenges presented by diabetes. An appreciation of the individual experience of living with diabetes, and the expertise borne out of this experience, are characteristics of the 'differentiated self' and this enables individuals to focus on life goals rather than the universal recommendations of living with the disease.

Lawson, Lyne, Harvey and Bundy (2005) identified 'expert patients' as one group of people with diabetes who are less likely to attend specialist clinics believing that they were personally equipped with the knowledge and skills to manage their

diabetes without outside influence. This may suggest that the 'differentiation of self' which Paterson et al. (1999) refer to may lead to non-attendance at clinics. However, this does not infer that those who exhibit less control over their diabetes will be more likely to attend clinics as Lawson et al. found a 'high fear' group with low perceptions of control over their diabetes were also unlikely to attend. In this case fear resulted in avoidance behaviour. Also unlikely to attend were the 'low arousal/low motivation' group who did not perceive diabetes to be a serious disease, (due to its lack of visibility to others).

With reference specifically to the experience of young adults with diabetes (aged 16-22 years), it would appear that progression to a state of integration and acceptance of diabetes is difficult to achieve. Schur, Gamsu and Barley (1999) noted the fear of being controlled by diabetes led participants to search for a balance between diabetes and lifestyle. By managing diabetes, they were able to confine it to its allocated place and carry on with the rest of their lives. The fear of future complications was dealt with through 'adaptive denial', whilst the fear of social non-acceptance (due to diabetes) was dealt with by developing an identity independent of diabetes. Schur et al.'s findings suggest a separation of individual and diabetes. As this is distinctive to the theories proposed by Hernandez (1996) and Paterson et al. (1999), it may be the case that young adults with Type 1 diabetes learn to live with diabetes in ways distinctive to older adults (participants in Hernandez's study ranged from 24 to 39 years, and 24 to 81 years in Paterson et al.'s study). Further, as the processes suggested by the authors above stress their ever-evolving nature, it may be the case that the participants in Schur's study are yet to reach the 'science of one' or 'transformation' stage in which diabetes becomes an integrated and accepted part of life. Huss and Enskär (2007) described the experience of adolescents living with Type 1 diabetes as 'a pendulum swinging between being normal and being different' (p. 30) and highlighted the emphasis their participants placed on feeling normal. It could be argued that such a fixation on normality would continue until a 'turning point' (Hernandez, 1996) brings about a shift in individual emphasis.

Rasmussen, O'Connell, Dunning and Cox (2007) explored how young women with diabetes managed the difficult transition from adolescence into adulthood. In this case, women strove to restore stability to their lives in response to the imbalance

caused by transitions. This was achieved by giving greater attention to blood-glucose levels, establishing relationships with health professionals based on openness and trust, and putting things in perspective by comparing their situation with others. This all formed part of a process of normalization whereby diabetes was accepted, enabling participants to move on. The authors noted that 'as the personal and social context changes, people's perspectives shift in the degree to which illness is in the foreground or background of their reality' (p. 307), thus people's experience of illness, and the way they live with it, is ever-changing. Similarly, Sparud-Lundin, Öhrn and Danielson (2009) referred to the ongoing redefinition of relationships and identity in young adults with Type 1 diabetes. In this case, progression to adulthood brought with it a shift in the way diabetes was managed with parents handing over responsibility to the young person with diabetes. This resulted in a growing awareness of one's own strengths, weaknesses and emotional reactions which serve to redefine the self.

The individual and evolving nature of life with diabetes has also been noted in research which looks at the self-management of the disease. Paterson and Thorne (2000) propose a developmental model of expertise in diabetes self-management. Expertise is reached via four phases: 'passive compliance' (in which the management regimen advocated by health professionals is strictly adhered to), a brief phase of 'naïve experimentation' (marked by 'trial and error' alterations to the regimen without the necessary knowledge to ensure that these alterations are successful), 'rebellion' (denial of diabetes by ignoring the demands of the management regimen – also viewed as an attempt to assume control), and finally 'active control' in which a conscious decision is made to take personal control of the management of their diabetes. Participants stated that 'assuming control entails a redefinition of the meaning of the illness, blood glucose testing, relationships with others, and the self as the person who lives with diabetes' (p. 412). The result of 'active control' was the ability to live a normal life in which illness was accepted and a good quality of life was achieved. In other studies, expertise enabled people with diabetes to deal with unexpected blood-glucose levels (UBGL) by using strategies of 'vigilance, past review, and physiological interpretation to determine the cause of the UBLG and to resolve the problem' (Paterson & Thorne 2000, p. 155). While Thorne and Paterson (2001) concluded that 'each individual with a disease brings to the management



problem all of the unique and extraordinary circumstance of his or her life and context' (p. 88), in order to live well and maintain a sense of normality, individuals need to contain thoughts regarding self-management to their subconscious whenever necessary. Whilst participants acknowledged that successful self-management will result in minimum daily incidents of hypoglycaemia and hyperglycaemia, real success is evaluated by the extent to which they can live a normal life.

#### *2.2.5 Qualitative research into Type 2 diabetes*

The emphasis on the 'control' referred to in the qualitative literature into Type 1 diabetes is also observable in studies involving people with Type 2 diabetes. Broom and Whittaker (2004) noted the multiple meanings associated with control: 'Control is simultaneously a biomedical statement about the management of blood sugar levels, a description of responsible compliance with medical regimes, an ability to manage other life stresses, and the triumph of the rational self over the disorder of the physical body' (p. 2380). They found that 'control' has implications for the moral identity of someone with diabetes, as being 'out of control' in terms of blood-glucose levels results in the identification as a 'bad diabetic'.

The potentially evolving nature of self-management strategies observed in people with Type 1 diabetes can also be viewed in those with Type 2 diabetes. However, there is a unique factor influencing the extent to which individuals assume control of self-management of Type 2 diabetes. In contrast to Type 1 diabetes (which is an autoimmune disorder) the causation of Type 2 diabetes is associated with both genetic and lifestyle factors. Parry, Peel, Douglas and Lawton (2006) noted that participants' explanations of causation were linked to their style of disease-management. For example, participants who believed their diabetes was caused by their lifestyles took personal responsibility for the management of their diabetes (as lifestyle is within their control), whilst those who identified genetic factors as having caused diabetes were happy for health professionals to assume control of the disease and participants assumed a passive role in management. However, accounts of causation are open to change, as Lawton, Peel, Parry & Douglas (2008) demonstrate in their longitudinal study. They found that participants who made reference to 'controllable' factors, such as poor diet, in their original accounts of causation tended

to shift accountability to 'uncontrollable' factors (hereditary factors) in light of observing deterioration in their condition over time, despite attempts to adhere to the treatment regimen.

Further qualitative studies in the context of Type 2 diabetes also follow a focus on self-management of the disease. Oftedal, Karlsen and Bru (2010) explored adults' (with Type 2 diabetes) perceptions of the support they receive from their health professionals. They reported that people with Type 2 diabetes need practical support relating to the everyday challenges of living with diabetes, as well as group-based support if motivation for self-management of diabetes is to be sustained. The authors recommended that healthcare professionals 'give more individualized instruction during self-management programmes' (p. 1506), thus acknowledging the complexities of diabetes management. The qualitative research conducted by Newton, Scambler and Asimakopoulou (2011) also focussed on the healthcare encounter. This particular study parallels my earlier discussion of the need to include *experiential knowledge* in biomedical research. In this case, the researchers examined the concept of *empowerment* and what it meant to health professionals treating patients with Type 2 diabetes. They identified contradictory accounts of what *empowerment* means and concluded that 'models of empowerment, which promote that HCP [healthcare professionals] bring clinical expertise and patient's lay expertise of illness to the medical encounter, are inadequately descriptive of how empowerment approaches are actually engaged with, by HCPs' (p. 326).

#### 2.2.6 Quantitative Research into Diabetes

There is a vast body of quantitative literature into diabetes, the majority of which is informed by mainstream health psychology. I would argue that given the economic cost of diabetes to health services (approximately £1 million per hour in the case of the NHS ([www.diabetes.co.uk](http://www.diabetes.co.uk))) efforts to identify ways of reducing such cost is unsurprising. Implicit in this body of quantitative research, is a belief that the goal of self-management of diabetes is optimal glycaemic control. It is when such glycaemic control is obtained, that the risk of diabetes-related complication is reduced alongside the potential cost to the health service.

Accordingly, research into the ways of improving glycaemic control is common. In the case of patients with Type 1 diabetes for example, Winkley, Landau, Eisler and Ismail (2006) reviewed the effectiveness of psychological interventions to improve glycaemic control. They concluded that psychological interventions (based on cognitive behaviour therapy) can slightly improve glycaemic control in children and adolescents with diabetes but have no effect in adults. Zoffman and Lauritzen (2006) examined the impact of guided self-determination (GSD) on life skills and glycaemic control of patients with Type 1 diabetes. Referring to the work of Zoffman (1995), they explain the aim of GSD as 'increasing the patients' life skills, defined as "those personal, social, cognitive and physical skills that enable people to control and direct their lives, and to develop the capacity to live with and produce change in their environment" (p. 79). The authors concluded that GSD was effective in improving the life skills and HbA1c levels of patients with persistent poor glycaemic control over a one year period. The interaction between stress, learned resourcefulness and metabolic control was investigated by Aikens, Wallander, Bell and Cole (1992). They found a positive relationship between variability in daily stress and future poor glycaemic control, thereby highlighting the need for clinical intervention to target stress. They also noted that regimen adherence failed to moderate this relationship between stress and metabolic control. The authors also found (to their surprise) that 'learned resourcefulness' ('a set of behavioural and cognitive skills used to self-regulate internal responses that interfere with behaviour', p. 114) was positively correlated with poor metabolic control. Among some of the possible suggestions offered by the authors as to why this correlation may occur is that learned resourcefulness serves to control 'internal states', and thus may function to suppress the cues associated with 'diabetes-related internal sensations' (p. 117).

While the research above has considered the potential of interventions to improve glycaemic control, other researchers have explored the factors which impact on one's ability to self-manage diabetes (and thus control blood-glucose levels). Using the framework of the extended health belief model (EHBM) in their research involving 16 to 25 year olds affected by Type 1 diabetes, Gillibrand and Stevenson (2006) found that adherence to the recommended diabetes regimen was largely predicted by levels of family support, with high levels of family support promoting increased adherence.

In their study of work-related and personal factors in diabetes self-management, Weijman et al. (2005) found that the level of workload, social support, coping styles and levels of self-efficacy each served to impact upon self-management activities. Specifically, a high workload resulted in the perception of injecting insulin as a burden; the level of social support ‘was positively related to the frequency of self-management in Type 2 diabetes and negatively related to the sense of being burdened by dietary self-management in Type 1 diabetes’ (p. 87); an avoidance coping style was associated with less frequent monitoring of blood-glucose levels and an increased sense of being burdened by such monitoring; and a low level of self-efficacy was associated with the perception of all self-management activities as a burden. The authors also noted that participants with Type 1 diabetes and with a higher level of education engaged in more frequent blood glucose monitoring. Al-Khawaldeh, Al-Hassan and Froelicher (2012) also highlighted an association between self-efficacy and self-management of diabetes in their mixed-method study of Jordanian patients with Type 2 diabetes. Their findings showed participants with greater self-efficacy and greater diet self-management behaviour had lower HbA1c levels, while insulin usage by this group was a predictor of poorer glycaemic control.

I argue that these studies have attempted to compartmentalise life with diabetes into personal, social and demographic factors (amongst others) in order to understand the impact of each of these factors on diabetes self-management, and thus make recommendations for improved interventions. However, what these studies have illustrated is that it is impossible to consider these factors in isolation. Rather, diabetes is managed by an individual with a host of fluctuating complexities, which intertwine to produce various outcomes in terms of diabetes self-management and make the task of predicting control very difficult.

### **2.3 Children and Adolescents with Diabetes**

Given its popular association with onset during childhood years, and indeed its aliases as ‘juvenile diabetes’ and ‘early-onset diabetes’, it is unsurprising that there is a preponderance of research into children and adolescents with Type 1 diabetes. A review of this literature highlights the same complexities regarding main stream

health psychology concepts as those identified in Section 2.1.2. Specifically, Schilling, Grey and Knafl (2002) consider the concept of 'self-management'. As noted earlier with regards to the concepts of compliance and adherence, the authors highlight a lack of uniform definition of the concept of self-management and no differentiation in the literature between self-management of diabetes in adults and children. Following a concept analysis, based on 99 publications, the authors offer a working definition of self-management as an active and proactive process, consisting of varying activities and involving the potentially differing goals of both parent and child. Shilling et al. (2002) paper illuminates the complexity of diabetes self-management. Self-management is not a singular activity. Rather, it is an umbrella term for a plethora of activities and processes which, when combined, lend themselves to the management of diabetes.

The complexity of self-management is further illustrated by a body of research which highlights how the interaction of a number of diverse factors can influence children and adolescents' management of diabetes. For example, Hilliard, Wu, Rausch, Dolan and Hood (2013) identified 'older age, longer diabetes duration, ethnic minority status, unmarried caregiver status, insulin delivery via injections versus continuous subcutaneous insulin infusion, greater depressive symptoms, negative affect about BGM [blood-glucose monitoring], and diabetes-specific family conflict each predicted membership in a subgroup with poorer diabetes management and control' (p. 28). Borus, Blood, Volkening, Laffel and Shrier (2013) commented on the interaction of social context on adherence to blood glucose monitoring recommendations. They found that the odds of checking blood glucose levels were higher when participants had a strong desire to blend in than when their desire was not as strong. On the other hand, participants were less likely to check glucose levels when they wanted to impress those around them. The researchers refer to these social contexts as 'cold cognitive' and 'hot cognitive' situations respectively. The 'cold cognitive' situation requires the adolescent to passively fit in and thus results in discrete blood glucose monitoring in order to prevent the onset of hypoglycaemia which may cause embarrassment. In the 'hot cognitive' situation, the researchers argue that the social concerns of fitting in impair decision-making and the adolescent 'prefers to risk a major social embarrassment to avoid the perceived social awkwardness of the glucose check' (p. 582).

I would argue that Borus et al's (2013) reference to '*impaired* decision-making' infers a judgement as to what constitutes the *correct* blood glucose monitoring behaviour. It also suggests that the adolescent is a passive victim of the social context in which they find themselves. He/she who does not check their blood glucose levels in a 'hot cognitive' situation is not actively part of that decision but rather is blinkered by their environment. I would argue, on the other hand, that the adolescent is an agent in this decision-making process and that the desire to achieve normality, both in the 'cold cognitive' and 'hot cognitive' situations informs his/her decision whether to engage in blood-glucose monitoring or not. I would also suggest that any attempt to frame 'self-management' as a succinct concept is complicated by the complexities that each 'self' brings to the process of management.

## **2.4 Diabetes and Gender**

### *2.4.1 Women and diabetes*

Research into women and diabetes has attended to a diverse range of topics. For example, Rasmussen et al. (2007), (discussed earlier) explored how young women with diabetes manage the transition from adolescence to adulthood. Kay, Davies, Gamsu and Jarman (2009) explored the issues inherent in women's experiences of living with diabetes. Their study identified women's concerns as relating to their relationships with their bodies, 'personal challenges', the impact of diabetes on their relationships, and 'changing and adapting'. Lund (1996), explored the health issues unique to women with diabetes such as the effect of the menstrual cycle on glycaemic control and the intentional omission of insulin in order to lose weight.

Other studies involving women with diabetes have also served to highlight the complexity of diabetes self-management. For example, Anderson et al. (1995) conducted a study of Chinese-Canadian and Euro-Canadian women with diabetes and found that ethnicity alone did not determine how a woman managed her illness. Rather, the authors referred to the management of diabetes as a 'multi-faceted phenomenon, which has to be understood within the mediating circumstances of a woman's life' (p. 181). This is in keeping with much of the literature reviewed in

this chapter and supports the argument presented in this thesis, that we must attend to the *holistic* experience of living with diabetes rather than a compartmentalized study of self-management of the disease. These sentiments have also been shared by Gomersall, Madill and Summers (2012) who conducted a dialogical analysis of women's accounts of poorly controlled Type 2 diabetes. In keeping with the findings of qualitative research considered earlier in this chapter, the authors noted that 'the truths by which participants lived shifted as they encountered new perspectives and experiences' (p. 378), and they called for a progression from the 'static' notion of self-management towards a conceptualisation of life with chronic illness that includes 'personal goals, values and embodied experience in context' (p. 391).

#### *2.4.2 Men and diabetes*

Leonard (2004) argues that the male perspective of diabetes-related health issues 'have been either inadequately investigated or not investigated at all' and adds that 'health care providers can better respond to the needs of their male patients if they understand these patients' worldview' (Leonard, 2004, p. 206). More recently, Gomersall, Madill and Summers (2011), stated, with reference to research examining self-management of Type 2 diabetes, that 'no authors had yet studied exclusively the perspectives of men' (p. 864). Of the research that does exist into men and diabetes, the findings compliment some of the research into men with chronic illness in general, in which efforts are made by men to minimise the presence of diabetes in their lives. In Koch, Kralik and Taylor's (2000) study of men with Type 2 diabetes this was achieved by viewing diabetes as part of life and experimenting with their lifestyles in order to establish an individualized approach to diabetes care. This process is referred to as 'normalization' (Peyrot et al. 1988) and was distinct to the ways in which the authors noted that women responded to life with diabetes. As opposed to 'normalizing' diabetes into their lives, the women they had worked with previously, focussed on the restrictions and changes enforced by diabetes.

Hjelm, Bard, Nyber, and Apelqvist, (2005) demonstrate the variations in beliefs about health and diabetes held by men of different ethnic origin. Their study demonstrated the varying importance attached to employment, sexual functioning and wealth by these men, alongside differences in information-seeking behaviour



and beliefs regarding the causation of diabetes. In the case of English- and Spanish-speaking Hispanic men, Rustveld et al. (2009), found that while participants understood the recommendations of their diabetes-regimens, lack of skills, lack of will-power and reluctance to change culturally-rooted behaviours emerged as significant barriers to diabetes self-management. The interaction between ethnicity and diabetes was also examined by Jack, Toston, Jack and Sims (2010) in their study of black men with diabetes in the United States. They argue that there is a lack of consideration given to how attributes of masculinity can influence the diabetes self-management behaviours of this group. When combined with a lack of health insurance and the absence of consistent sources of health care, failing to attend to the influence of masculinity on diabetes self-management has resulted in ‘a disproportionate burden of diabetes’ (p. 7) upon black men in the United States.

Further research looking specifically at men with diabetes revolves around the issue of sexual-functioning. Bacon et al., (2002) found an association between duration of illness and the risk of developing erectile dysfunction amongst men with Type 2 diabetes. Corona et al. (2004) identified a greater severity of erectile dysfunction amongst diabetic patients with diabetes mellitus-induced erectile dysfunction, while De Barardis et al. (2002) found that erectile dysfunction was associated with worse psychological adaptation to diabetes which resulted in worse metabolic control. Each of these studies concentrated on heterosexual diabetic men, neglecting the experience of gay and bisexual men with diabetes. Jowett, Peel and Shaw (2011) attended to this gap in their research and highlighted several sexual problems experienced by gay and bisexual men with diabetes. In addition to erectile problems, thrush and hypoglycaemia served to affect sexual-functioning, as did the cultural and relational context of these men.

#### *2.4.3 Comparative Studies*

In order to move beyond the arena of diabetes-related sexual-functioning and gain an understanding of how men live with diabetes, we must turn our attention to gendered studies which often serve to highlight the dissimilarities between diabetic men and women. Hjelm and Nambozi (2008) showed in their study involving Ugandan men and women, that men with diabetes focused on issues concerning the affordability of



drugs, sexual-functioning and the ability to engage in daily activities. Women on the other hand, were concerned with well-being and support, and also expressed a greater awareness of the risks associated with diabetes. In relation to disease-management, Peel, Parry, Douglas and Lawton (2005) suggest that gender interacts with the way individuals with Type 2 diabetes manage their diet. They found that women managed their diets individually while men 'constructed their diabetic diet as being a broader familial issue that was not their concern alone' (p. 788). Women, unlike men, also spoke about craving certain foods and feeling the biological 'urge' to eat.

In terms of coping, studies have demonstrated that women with diabetes (both Type 1 and Type 2) utilise coping strategies with a social support basis, whilst men adopt an active-coping approach (Enzlin, Mathieu, & Demyttenaere, 2002). These findings were echoed by Ferrand, Perrin and Nasarre's (2008) study with members of a patients association who had Type 2 diabetes. In this case women attached importance to the emotional support obtained from attendance at group meetings whilst men with diabetes emphasised the opportunity to increase knowledge and develop skills. Such differences in coping mechanisms do not infer a difference in blood-glucose control as Enzlin et al. (2002) demonstrated that there was no significant difference in the glycaemic control of men and women in their study. It is also noteworthy that such distinctive coping strategies of men and women are not unique to those affected by diabetes. In Munir, Pryce, Haslam, Leka and Griffiths (2006) study of gender differences in the management of chronic illness in the workplace, women suggested that receiving emotional support was important in terms of their illness management.

The observed differences in coping mechanisms of diabetic men and women (and men and women affected by chronic illness in general), are representative of the gendered coping strategies of the general population irrespective of disease. This suggests that gender may interact with the way men and women experience life with diabetes. This possibility has been explored by Broom and Lenagh-Maguire (2010) in their study involving adults with Type 2 diabetes. They found variation in the way gender interacted with diabetic life. For example, traditional gender roles were evidenced in men's accounts of work and the way in which work intruded on their

ability to adhere to the diabetes regimen. Discussions of food and meal-time were reflective of traditional gendered discourses with women positioned as responsible for feeding the family. Exceptions to these conventional gendered roles were also identified as some men assumed responsibility for food preparation whilst others were involved in the care of their diabetic wives. In each case the authors highlighted additional elements which may be at play including unemployment, age, language and cultural competence, and disability. The suggestion is therefore that 'gender is intertwined with other elements of social structure which multiply the forms of gender available' (p. 207).

The complex interaction between gender and health was also noted by Williams (2000) in her study of teenagers with diabetes and asthma. In this case girls were found to incorporate illness into their personal identities whilst boys kept asthma or diabetes as invisible as possible. Boys, in comparison to girls, placed emphasis on the sport and exercise elements of their regimens, something which the authors suggest serves to construct masculine identity. Girls, in contrast to boys, often spoke about diet and expressed guilt discussing poor diet.

## **2.5 Men's Health**

In order to attend to the literature surrounding men's health, one must begin with a consideration of the term *masculinity*. The Oxford English Dictionary subsumes the term 'masculinity' under their definition of 'masculine', which they explain as 'relating to men'. Inherent in this common definition of masculinity is the construction of 'men' as a homogeneous group, with shared and identifiable traits, which are accounted for through biological determinants. Indeed this reductionist view of men's behaviour, as being linked to their biological disposition, informs the *normative* view of masculinity. This view aligns the typical traits of masculinity with, for example: aggressiveness, competitiveness, hierarchy, promiscuity, territoriality, and political power (Connell, 1995).

However, this account of masculinity has been criticised for its reductionist standpoint and, in response to this approach, Connell (1995) argues that by broadening our viewpoint, 'we can see masculinity, not as an isolated object, but as

an aspect of a larger structure' (p. 67). Proposing a relational model of gender, Connell (1995) asserted that gender interacts with areas of social practice, such as race and class, and through these interactions multiple masculinities are developed. She presented the main patterns of masculinity in the current Western gender order as 'hegemonic', 'subordinated', 'marginalized' and 'complicit'. In this case, 'hegemonic masculinity' referred to the configuration of gender required to sustain the *current* dominance of men and of patriarchal society. This form of masculinity defines what it is to be a 'real man' and is characterized by 'toughness, unemotionality, physical competence, competitiveness and aggression' (Lee & Owens, 2002, p. 3). 'Subordinate' masculinities, then, refers to masculinities which are treated as inferior in patriarchal society, and thus subordinate to hegemonic masculinity. These may include gay masculinity which Connell (1995) explains (in terms of patriarchal ideology) as: 'the repository of whatever is symbolically expelled from hegemonic masculinity' (p. 78). 'Complicit' masculinity accounts for those men who benefit through patriarchy, without fulfilling the normative standards of hegemonic masculinity. These men, Connell explained, realise 'the patriarchal dividend' (p. 79). Finally, 'marginalized' masculinity, unlike 'subordinate' masculinity, refers to men who 'become marginalized from full participation in society by material practices' (Robertson, 2007, p. 33). While presenting masculinities in these categories, Connell also stressed that these are not fixed definitions. Rather, 'structures of gender relations are formed and transformed over time' (p. 82), while also being open to 'internal contradiction and historical disruption' (p. 73).

Courtenay (2000) gave the following explanation of the interaction between hegemonic masculinity and men's health:

*'A man who enacts gender as socially prescribed would be relatively unconcerned about his health and well-being in general and would place little value on health knowledge. He would see himself as stronger, both physically and emotionally, than most women. He would think of himself as independent, not needing to be nurtured by others. He would develop close friendships, and his social networks would be small. He would be unlikely to ask others for help. Work and employment would be central to his sense of*

*self and essential for maintaining his self-esteem. The intense and active stimulation of his senses would be something he would come to depend on. He would face danger fearlessly, disregard his risks, and have little concern for his own safety. He would lack the vocabulary to describe physical sensations and would have difficulty identifying and expressing most of his emotions. However, he would consider anger to be acceptable, particularly when expressed physically. He would view physical violence as a sometimes necessary part of life. He would not be interested in learning about health, nutrition, or cooking, and he would be unconcerned about his weight, diet, or hygiene. Finally, he would adamantly reject doing anything that he or anyone else would consider feminine' (p. 10).*

In line with this account, Courtenay (2000) argues that men who wish to portray manhood, may adopt unhealthy beliefs in order to do so. Femininity, which is traditionally associated with an interest in health, is rejected by rebuffing health. However, this understanding of 'the doing of health is a form of doing gender' (Salonstall, 1993, p. 12) is too simplistic, as it implies that hegemonic masculinity and femininity are two distinct and homogeneous groups. While Connell's theorising of masculinity is generally applauded for allowing diversity through the formulation of multiple masculinities, it has also received criticism for a *lack* of diversity in its explication of hegemonic masculinity and the ways in which it is performed. For example, Wetherell and Edley (1999) concluded that there 'is a multiplicity of hegemonic sense-making relevant to the construction of masculinity identities' (p. 18). They noted that men in their study portrayed themselves as 'ordinary' (as opposed to macho) in what could be interpreted as an alternative way of demonstrating hegemonic masculinity; while Speer (2001) highlighted the context-sensitive ways in which masculinity is constructed. Thus, as Gough and Robertson (2010) posit, the argument that masculinity as a whole is bad for one's health is too simplistic and instead, a range of factors interact to inform men's health practices. These include discourses of health and gender, access to resources, and the ability to maintain a 'normal' embodied-self.

Indeed, the contradictory findings of studies examining the relationship between masculinity and health, are further evidence of the need to attend to multiple factors, which interact with gender, to inform men's health practices. For example, Mahalik, Levi-Minzi, and Walker (2007), concluded that 'one contribution to Australian men being more likely than Australian women to eat high-fat foods, exercise less after the age of 35, drink alcohol excessively, smoke, use illegal drugs, engage in life-threatening behaviours, avoid their general practitioner and preventive care....may be that these health behaviours are part of their identity as men' (p. 246). Contrastingly (specifically in relation to diet), Sellaeg and Chapman (2008) found that the food ideals of Canadian men living alone included 'being conscious and organized with respect to food and eating so that they could regularly eat meals prepared at home from healthy foods and ingredients' (p. 125). These findings illustrate that 'being a man' alone does not explain choices regarding consumption and diet. Rather the strength of cultural representations of masculinity may influence men's choices. Gough (2007) highlighted the dominance of hegemonic masculinities in contemporary newspaper representations of men, food and health. He concludes that 'the media reliance on stereotypes of masculinity and gender differences generally require deconstruction so that more sophisticated and hopefully effective health interventions for men incorporating diet can be designed' (p. 336).

Such contradictory findings are also noted with regards to the masculine ideals of older men. While Robertson (2007) suggests that the ideals of men change throughout the lifecourse (progressing from showing a lack of interest in health, to recognising a moral responsibility that they *should* attend to their health), Davidson et al. (2009) found that older men 'remain structurally situated within the same dominant ideology/discourse as younger men' (p. 122).

In the wake of a chronic illness diagnosis, the traditional separation between masculinity and an interest in health becomes difficult to sustain, as the male body is rendered open to medical scrutiny in order to assure physical well-being and survival. However, despite this potentially uncomfortable shift in territory, from indifference to health interaction, research would suggest that men have found a means of sustaining masculine identity within the medical setting by finding a suitable fit for both treatment of illness and the expression of gender identity. For

example, Broom (2004) found that men with prostate cancer opted for the form of treatment that allowed them to sustain sexual functioning (even if an alternative treatment may pose as a more effective cure), suggesting that the ability to express masculinity through sexual ability was of greater importance than physical health. Other researchers have suggested that men with chronic illness separate their identity as a man, from their identity as an 'ill' person, and achieve this by minimising the impact illness has on their lives (Charmaz 1994, Goffman, 1963). While other researchers have cited the presence of a female partner as *enabling* men to engage in health-related behaviour while, at the same time, preserving their masculinity (e.g. Davison & Meadows, 2009). This point is discussed further in section 2.6 (below).

In sum, a review of the literature into men's health points to the need to attend to the possible expressions of multiple masculinities, and the varied expressions of hegemonic masculinity. One must be mindful of the context within which men's engagement with health is situated, and the potential influence of several factors on the nature of this engagement.

## **2.6 Men, their partners, and chronic illness**

While hegemonic constructions of masculinity position men as uninterested in health, research would suggest that the presence of a female partner provides men with the opportunity to legitimately engage in health-related behaviours. For example, Davidson and Meadows (2009) found that female partners provided men with, what Noone and Stephens (2008) refer to as, a 'legitimate user position'. In this case, men present their engagement in health as a means of appeasing their spouses. In this way, their masculine identity is protected by continuing the alliance of an interest in health with femininity – in this case, their female partner is to blame. Similarly, Seymour-Smith and Wetherell (2006) found in their study of couples affected by cancer that female supporters enabled their male partners to engage in emotional talk about their illness. Thus, the presence of a female partner, it would appear, enables men to safely tread the line between masculine indifference and feminine interest in health.

In addition to enabling men to seek medical help, and express their emotional

reaction to illness, partners are often actively engaged in the management of illness and affected by the presence of disease. Arrington (2005) documented the way men with prostate cancer portrayed their wives as: health monitors and caregivers; primary emotional support sources; and self-less supporters. Research by Öhman and Söderberg (2004) illustrates the potential fall-out of these roles, as family members, who care for an ill relative, experience a reduced sense of individual freedom and an increased sense of responsibility for the care of the ill person. Similarly, Rees, O'Boyle and MacDonagh (2001) noted that while partners may benefit from an increased sense of pride and self-esteem (resulting from the caring role) they can also experience 'worsened health, impaired social and family life and increased stress, anxiety and depression' (p. 563).

Given the influence of partners on men's health, it is surprising to note a lack of literature which has examined how men with diabetes, and their partners, negotiate life with this chronic illness. Rather, research has been carried out with couples in which either male or female partner have lived with diabetes, and no reference is made to the possible interaction of gender with the results. Stephens, Rook, Franks, Khan and Iida (2010) examined partners' use of social control strategies to improve dietary adherence in their diabetic partners. They found that encouragement strategies were associated with better adherence to the recommended diet while warning strategies had the opposite effect. In terms of spousal support, Trief et al. (2003) evidenced both helpful and unhelpful behaviours in spouses of people with diabetes. Included in the helpful behaviours they listed activities relating to dietary control and regimen reminders, while 'nagging' was included in their account of unhelpful behaviours. High levels of expressed emotion (EE), amongst partners, was identified by Wearden, Tarrier and Davies (2000) as having a detrimental effect on patients self-rated management of diabetes (although the authors did not find an association between EE scores and blood-glucose control).

Research involving couples affected by diabetes, has also considered the interaction between the marital relationship and adjustment to diabetes. In this case, Trief, Ploutz-Snyder, Britton and Weinstock (2004), found moderate support for their hypothesis that a better marital relationship predicts better adherence to the diabetes regimen. While Peyrot, McMurray, and Hedges (1988) found that 'when a patient

and spouse disagree regarding the degree of responsibility each should have for health matters, the quality of the marital relationship suffers' (p. 373). These findings would suggest the two-way interaction between diabetes and marital relationship: the better the relationship, the greater the adherence to diabetes regimen; while, the greater the conflict regarding diabetes, the quality of marital relationship suffers

While these studies give an important insight into the dynamics of a relationship affected by diabetes, we still know very little about how couples, in which the male partner has Type 1 diabetes, experience life with this disease. It may be the case that the gender of the diabetic in the couple has little impact on the couples' experience of the disease – this would be a possible explanation for the absence of this kind of gendered research. However, research has pointed to the ways in which female partners *enable* men to show an interest in health (as discussed earlier in this section). Additionally, other studies would suggest that gender does indeed have an influence on the couple's experience of illness. For example, De Ridder, Schreurs and Kuijer (2005) examined the helpfulness of spousal support to patients with asthma and diabetes and identified a gender effect in relation to 'protective buffering': 'female patients experience worse physical health when their husbands hide their concerns whereas male patients, in contrast, benefit when their wives do not discuss their worries with them' (p. 506).

Based on the literature reviewed in this section, it would appear that illness extends from the confines of an individual experience, to affect the couple. Research has shown that the presence of female partners provides men with the opportunity to engage in health whilst safeguarding their masculine identity. The frequent position of partners in a caring role serves to impact on their quality of life. Couples affected by diabetes experience the wider effects of this disease on the quality of their relationship, yet little is known about how diabetes impacts on the lives of male diabetics or their partners.

## **2.7 Summary of Literature Review**

In this chapter, I have considered the biomedical and mainstream health psychology



research into diabetes. In particular, I have offered a critique of the MHP concepts of ‘compliance’ and ‘adherence’ and argued for a greater focus on the *holistic* experience of living with diabetes rather than the study of the ‘self-management’ aspect of the disease.

A review of the qualitative literature concerning diabetes, illustrates the changeable nature of life with the disease. These changes are in response to the individual’s growing understanding of diabetes, their increased recognition of the disease, and their growing expertise in the management of it. The importance of the satisfaction of personally held and health-related goals were also referred to, as was the multi-faceted issue of ‘control’.

With regards to gender and diabetes, the literature is marked by its absence of studies focusing exclusively on men’s experience of the disease. Therefore, what we know about how men live with diabetes, is borne out of limited research. The research which does exist, points to men's attempts to live a ‘normal’ life, by establishing an individual approach to the management of their disease. The fact that research into men and diabetes is dominated by studies examining the nature, and prevalence of erectile dysfunction, is possibly reflective of the reductionist approach to men’s health issues. In terms of traditional masculinity, sexual prowess and the ability to procreate are considered as important features of masculine identity. Thus, when these features are under threat, a focus on men’s health is justified in order to safeguard masculine identity.

A brief insight into the literature into men’s health was also provided. Here, the discussion surrounding the expression of masculinity through a rejection of health were discussed alongside recent research which points to the need to attend to the variation in the expression of masculinity.

Resulting from an apparent lack of research into men’s experience of life with diabetes, is an equal neglect of the couple's (in which the male partner has diabetes) experience of life with this disease. The research reviewed under this section of the chapter, points to the significant role of partners in enabling men to express an interest in health, whilst also preserving their masculine identity. Additionally,

research into the impact of chronic illness on relationships were considered, along with the positive and negative aspects of caring for an ill partner. Overall, such research illustrates that the quality of the relationship can inform the management of diabetes, while the responsibility of caring for an ill partner can lessen one's quality of life, whilst also providing a sense of pride.

## **2.8 The aims of this research**

Consistent with the perspective of critical health psychology, this thesis was guided by my strong belief that diabetes-research should be led by people with diabetes. It should give voice to the experiences of people with diabetes and serve the purpose of bettering the lives of this group, by attending to the issues made relevant by them. As evident in this literature review, the experience of men with diabetes has been largely neglected by researchers. As a consequence of this, so too has the experience of diabetic men and their partners. This study aims to address this gap.

My desire was to obtain an understanding of the holistic experience of living with diabetes, as made relevant by the participants in my studies. As such, I did not formulate specific research questions. Rather, I approached each study with a broad question. For example, Study 1 (Chapter IV) asked 'what is life like for men living with Type 1 diabetes?'. In Study 2 (Chapter V) I asked 'what do diabetic men talk about in an online forum?', and finally Study 3 (Chapter VI) asked 'how do families experience life in the presence of Type 1 diabetes?'.

While I have offered an insight into the theorisation of masculinity here, I did not approach this research with the goal of understanding how masculinity affected men's health. Rather, I entered into it prioritising the lived experience of my male participants, and their partners, as individuals affected by diabetes, and with the intention to attend to issues of masculinity if made relevant by my participants. I approach the analysis with an appreciation that masculinity can be expressed in many ways, with variations both between and within men, with regard to the importance they attach to the portrayal of masculine identity.

## Ch. III Methods

### 3.0 Overview and Aim

The previous chapter has demonstrated the need for qualitative investigation into men's experience of life with chronic illness. In particular, the need to attend to how men experience life with Type 1 diabetes has been established. In this chapter I discuss the methodological approach employed in this thesis, namely an abbreviated version of Grounded Theory (GT) in which GT methods were used from the point of data analysis onwards. I refer to my approach as an abbreviated version of GT because my data collection was not guided by the GT principle of *theoretical sampling*. Rather, all data were collected and subsequently analysed using the techniques outlined in this chapter. In section 3.1, I give an overview of the grounded theory approach and the theorists associated with it and I also discuss how this technique has evolved since its initial use. In section 3.2 I explain my rationale for using the GT approach and go on to detail my epistemic position in section 3.2.1. I attend to my dual status as researcher and diabetic, and the appropriateness of GT method to my research approach in sections 3.2.2 and 3.2.3 respectively. In sections 3.3 and 3.4 I detail the GT approach used in this research. I discuss the quality of my GT approach in section 3.6, before concluding with a summary of the chapter in section 3.7.

### 3.1 Grounded Theory

Grounded Theory was developed by sociologists Glaser and Strauss (1967) as a methodology to build theory from data in their studies of dying patients in hospitals. At the time of their research, sociological inquiry was dominated by quantitative studies. These studies were informed by positivist assumptions with the aim of making predictions about the world. For the most part, qualitative research was viewed as a precursor to quantitative research, and was believed to be less rigorous and less systematic than the latter. Glaser and Strauss (1967) challenged this notion in their book which detailed the strategies they used to build theory from data, and advocated these as a means of developing theory which would be grounded in the research data. In particular, Glaser and Strauss intended to construct abstract

theoretical explanations of social processes' (Charmaz, 2006, p. 5).

Glaser and Strauss' (1967) approach maintained that theory *emerged* from data following the careful utilisation of the grounded theory method of analysis. Strauss' subsequent work with Corbin (1990) moved away from this emphasis on emergence and argued instead that theory is *constructed* by the researcher after close engagement with the data. In the third edition of their book entitled 'Basics of Qualitative Research' Corbin writes, '*I agree with the constructivist viewpoint that concepts and theories are constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and/or lives, both to the researcher and to themselves*' (Corbin & Strauss, 2008, p. 10). Despite the variations between grounded theorists over the years, the core principles of the method have remained unchanged. That is, an emphasis on 'the move from data towards theory' (Henwood & Pidgeon, 1992, p. 101), recognition of the researcher's experiences and insights, and the utilisation of grounded theory analysis as an *iterative* approach in which data collection, coding and analysis should be carried out simultaneously.

Charmaz's (1990, 2006) version of grounded theory is informed by a social constructionist approach. She explained her use of the term 'social constructionist' in her work on chronic illness as meaning: '(1) Ill people's creation of taken-for-granted interactions, emotions, definitions, ideas, and knowledge about illness and about self and (2) Researchers' sociological instructions which they develop, in turn, by studying chronically ill people's constructions' (1990, p. 1161). She proposed the grounded approach in this type of research so as to 'provide physicians with alternative understandings of patients' beliefs and actions than those readily available in clinical settings' (1990, p. 1161). Indeed, her research offers a departure from a medicalized view of chronic illness to focus on the broader impact of 'suffering'. She argues that '[h]aving a chronic illness means more than learning to live with it. It means struggling to maintain control over the defining images of self and over one's life. This struggle is grounded in concrete experiences of managing daily life, grappling with illness, and making sense of it' (1991, p. 5). Charmaz highlights a 'loss of self' amongst those with chronic illness, borne out of: greater dependence on others; increased social isolation; 'being discredited'; and a heightened awareness of

one's departure from a 'valued-self' to an 'ill-self' (1983). Her subsequent work into the 'identity dilemmas of chronically ill men' (1994) explored men's experience of illness and highlighted how traditional assumptions of masculinity 'form a two-edged sword for men in chronic illness' (p. 283) as these assumptions can encourage men to recover from episodes of illness, whilst at the same time may 'narrow the range of credible male behaviours' and thereby 'foster rigidity in stance and set the conditions for slipping into depression' (p. 283).

### **3.2 Rationale for using GT**

My first encounter with Grounded Theory studies was through the work of Kathy Charmaz (1983, 1990, 1991, 1994, & 2006). Reading her work, from the perspective of someone with a chronic illness, I felt that she successfully conveyed what it is like to live with such an illness. The voice of the individual with illness came through in a way that I could identify with and inspired me to adopt this method in my own research.

#### *3.2.1 Epistemology*

My epistemological position is in keeping with that of 'repositioned' grounded theory method (GTM), as described by Bryant and Charmaz (2010):

*It is realist to the extent that the researcher strives to represent the studied phenomena as faithfully as possible, representing the 'realities' of those in the studied situation in all their diversity and complexity. A repositioned GTM assumes that any rendering is just that: a representation of experience, not a replication of it. It is interpretivist in acknowledging that to have a view at all means conceptualizing it....A repositioned GTM bridges defined realities and interpretations of them. It produces limited, tentative generalizations, not universal statements. It brings the social scientist into analysis as an interpreter of the scene, not as the ultimate authority defining it. And this method acknowledges the human, and sometimes non-human, relationships that shape the*

*nature of inquiry*'. (pp. 51-52).

I believe that the accounts participants shared with me, and the accounts shared in online forums, represents the realities of these particular individuals affected by diabetes. Through my analyses of these data, I offer a representation of these participants' lived experience of diabetes. As there has been very little research into men's experience of living with Type 1 diabetes, I felt that the use of GT would enable me to generate theory based on the accounts of my participants. Additionally, as there were some diversity in my sample of participants (with regards to age-range and duration of diagnosis) a method which required a small homogenous sample, for example IPA (Smith, 2004), would not have been suitable.

### *3.2.2 Dual status as researcher and diabetic*

As a person with Type 1 diabetes, I had many similarities with the participants in my research. For example, we shared knowledge of the medical side of diabetes - including the symptoms which precede a diagnosis; the treatment of diabetes with insulin injections (and the diet and eating schedule necessitated by this regimen); the routine medical assessments of blood tests, retinopathy scans, and neuropathy indicators. There was also an inevitable shared understanding of the physical sensations associated with episodes of hypoglycaemia and hyperglycaemia.

On the other hand, my experiences of diabetes also set me apart from my participants. Whilst I spent the first two years of my 'diabetic-life' on a regimen of four insulin injections daily (accompanied by a strict diet and eating schedule), at the time of interviews I had moved to insulin-pump therapy. The freedom afforded to me by my insulin-pump made me feel that the worlds of insulin injections and restriction were a million miles away. While I was still able to identify with my participants' experiences of injection therapy (and the lifestyle which accompanies it), I did so from my position where unexpected episodes of hypoglycaemia and hyperglycaemia are rare, and the scheduling of day-to-day events in order to accommodate injection and meal times is no longer a necessity. Given that my biography as someone with Type 1 diabetes informed my exploration of this research topic, it is necessary to

acknowledge these shared and divergent statuses.

My use of grounded theory approach shares the social constructionist underpinnings of Charmaz (1990, 1991, & 2006). In contrast to the account of the 'discovery' of theory put forward by Glaser and Strauss (1967), Charmaz argues that 'we construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices' (Charmaz, 2006, p. 10). This perspective rejects that an ultimate truth exists and rather, the grounded theories I propose in this thesis are constructed through my interactions, as someone with diabetes, with men and couples who are affected by the disease. Many participants stated that they chose to take part in the studies because I was also living with diabetes, and thus had a shared understanding of their experience. Additionally, the interviews were able to flow without participants feeling it necessary to explain diabetes terminology to me. Thus, I consider my dual status of diabetic and researcher, as both a resource and a potential influence which needed to be controlled for. Specifically, by 'controlled for', I refer to the need to be mindful of my status as a diabetic. I cannot completely bracket my experiences of diabetes or feelings towards diabetes out of my interactions with research participants, but I must acknowledge that I bring these experiences to the research. Importantly, I must *control* the influence of these experiences by allowing participants the freedom to make their own experiences relevant in the interview process, and by employing analytic strategies which ensure that the developing analyses are grounded in the data rather than imposed by me. By following the guidelines of grounded theory in my analysis (through the coding techniques detailed below) I have been able to focus on the data and limit the intrusion of my assumptions on the analytic outcome.

### *3.2.3 Appropriateness of research methodology and method to research questions*

My goal for this research was to offer a holistic account of living with Type 1 diabetes, as informed by diabetic men and their partners. As such, I wanted the research to be led by the participants rather than by a predetermined hypothesis based on previous findings in the literature. To achieve this holistic account, I kept the research question very broad: 'what is it like to live with Type 1 diabetes?'; thereby giving the participants the opportunity to make relevant *their* experiences.

The GT methodology facilitates the pursuit of such participant-led research (Charmaz, 2006). It recommends that one starts with a broad and general research question which gradually narrows around the findings of the analysis. It further recommends that the researcher delays the literature review in order to control the intrusion of findings from previous research in the area. The closeness to the data, achieved by the coding procedures of the GT method, means that the resultant analysis is firmly grounded in the participants' accounts, and my interpretation of these accounts.

#### *3.2.4 Grounded Theory as an established method in health-related research*

Earlier in this chapter, I have demonstrated the contribution of GT to research to the experience of living with chronic illness citing the works of Charmaz (1983, 1990 & 1991). Further, GT methodology has been used in the fields of men's health, chronic illness and diabetes, separately. For example, an exploration of nurses' responses to expert patients (Wilson, Kendall & Brooks, 2005); gender identity amongst teenagers with chronic illness (Williams, 2000); relationships and identity amongst young adults with Type 1 diabetes (Sparaud-Lundin, Öhrn, & Danielson, 2010); couples' experience of prostate-cancer (Boehmer & Clark, 2001); hetero-normative food practices and prostate cancer (Mróz, Chapman, Oliffe & Bottorff, 2011); and sexuality and intimacy in the context of cancer (Gilbert, Ussher & Perz, 2010). Thus, grounded theory has established itself as a prevalent method of analysis in the field of health-related research.

### **3.3 The approach utilised in this thesis**

In general, the grounded theory approach is an *iterative* process in which data collection, coding and analysis should be carried out simultaneously. The initial collection of data is informed by a broad research question. As data are coded and analysed, the research topic narrows around the emerging theory. Further data is then collected with the specific intention of exploring this emerging theory in more detail. By comparing the emerging categories and processes against their instances in the new data, the researcher is able to refine his/her theory. Glaser and Strauss (1967)



referred to this process as *theoretical sampling*.

As Glaser & Strauss (1967) advised, 'joint collection, coding, and analysis of data is the underlying operation [of grounded theory]' (p. 43). Due to the fact that my developing analysis did not direct further data collection, I am reluctant to refer to my work as a grounded theory study *per se* and rather choose to describe it as qualitative research which has used the principles of grounded theory from the point of analysis onwards.

The methods of data collection used in this thesis included both semi-structured interviews (Study 1- Chapter IV and Study 3 - Chapter VI) and the harvesting of postings to online forums (Chapter V). I choose this combined approach in order to obtain a comprehensive data corpus which would account for the experiences of men who are comfortable in sharing their accounts in a face-to-face interaction as well as those who may prefer to disclose their experiences under the veil of anonymity afforded by online message boards. While some qualitative researchers may be critical of the use of interview data (e.g. Potter & Hepburn, 2005), and instead promote the analysis of naturally occurring data, I believe that intensive interviewing can go 'beneath the surface of ordinary conversation' (Charmaz, 2006, p. 26) and draw-out topics which otherwise remain silenced. Additionally, I do not believe that conversations about living with diabetes take place 'naturally'. Since my diagnosis I have had two check-ups per year with a private consultant along with additional meetings at diabetes-clinics and have only been asked on one occasion how I feel about diabetes. This question was scheduled as part of a list of health-related questions which included questions regarding the frequency of hypoglycaemic events, the minutes of exercise per day and number of units of alcohol I consume per week. My response of 'fine' ticked a box and allowed my consultant to progress to the next question. Indeed my experience is not unique, as the four participants in my MSc research informed me that until taking part in my study, they had never been asked, nor had they ever discussed, their feelings about diabetes. For these participants, participation in the research provided them with the opportunity to articulate their experiences for the first time. Peel, Parry, Douglas and Lawton (2006) noted that one of the reasons participants engaged in interviews was due to the 'therapeutic aspects of interviewing', in which interviewees are provided with an

opportunity to 'get it off my chest'. At the same time, I acknowledge that there are some topics which may be important to participants however they may not feel comfortable talking about these topics in a face-to-face interaction. The data-set comprising of postings to an online forum was valuable in their own right as a source of data representing the unsolicited sentiment of the forum-users. Additionally, this data served to bridge any potential data-gap which may result from a reluctance to discuss certain topics in an interview setting.

### *3.3.1 Data Collection – Interview studies (Chapter IV and Chapter VI)*

According to Glaser and Strauss (1967), the 'process of data collection is controlled by the emerging theory' (p. 45), however in the case of this thesis, the theories I propose are *constructed* through my engagement with the original data-set only. Whilst some of the data collection overlapped with analysis of earlier interviews, this was not done with the intent to pursue emerging theoretical insights. I began data collection prior to committing to a particular method of analysis for my research. My focus was on the collection of quality data rather than the procedures of a particular method. By the time I had researched and chosen GT as my method of analysis, I had already carried out the data collection for Study 1 (Chapter IV). At this point, I was prepared to return to the field for further data collection if necessary, however I found during my analysis that my corpus of data sufficiently supported the developing theory. Glaser and Strauss (1967) stated, 'grounded theory may take different forms' (p. 31) and later Corbin and Strauss (2008) emphasized that 'techniques and procedures are tools, not directives' (p. 12) - aside from this variation in data collection, my approach to the analysis follows the main principles of Grounded Theory methodology.

As the process of ethical clearance associated with the NHS is quite lengthy, I opted to recruit participants through support groups, press-releases, and via snowball sampling through colleagues and friends (both in the UK and Ireland). I contacted diabetes support-groups in the Nottinghamshire area in the hopes that I could advertise my research at their meetings. However, I was not granted access as the organisers felt it may intrude too much on the users of the support-group. I turned my attention to recruiting through other means and organised a press release through

the University. Resulting from this press release, details of my research were published in a number of local newspapers and I had the opportunity to discuss my research, and need for participants, on two radio stations (BBC Radio Nottingham and Mid- West Radio, Ireland). I also recruited participants through 'snowball sampling', in which friends of mine passed details of my research to the diabetic men they knew and the men interested in taking part contacted me directly to do so. I was fortunate, through snowball sampling, to recruit men who had fallen away from their diabetes clinics as well as men who actively attended their clinics and are engaged in their health.

In the case of the empirical study detailed in Chapter IV, fifteen men were recruited as participants. Five of these participants contacted me following a radio interview, regarding the research, in the UK and another in Ireland. In each case I described the nature of the research and my own status as someone with Type 1 diabetes. Participation in the research was presented as an opportunity for men to talk about how they have experienced life with diabetes and share this account with someone who also has first-hand knowledge of the disease. The remaining ten participants were accessed through snowball sampling. Friends or colleagues of mine passed on details of the research to men who they knew were living with Type 1 diabetes. These men then contacted me directly to express an interest in taking part. All participants were required to be over 18 years of age. Recruitment was designed to provide a good spread of ages and this was achieved by ensuring there was at least 1 participant in each 10 year age band (e.g. 20-30, 30-40, 40-50, 50-60, 60-70). The mean age was 41.3 years. All participants were either White Irish or White English, and observed to be heterosexual based upon references they made to 'girlfriend' or 'wife' during the interviews (although I am aware that this may not be an accurate reflection of sexuality). There were no requirements on length of time diagnosed with diabetes. The mean length of time since diagnosis was 25 years. Participant details, such as ethnicity, employment status, duration of diagnosis and relationship status are presented in Table 1 (below). Details of the treatment regimen used by each of the participants are also provided. With the exception of 'Michael' and 'Ted', all participants were prescribed a regimen of 4 insulin injections per day (consisting of one slow-acting insulin and three fast-acting insulin injections). These injections were delivered by insulin pen. In the case of Michael, a regimen of two

bovine-insulin injections is followed, while Ted also injects twice daily but in his case a mixture of two types of insulin is used. Both Michael and Ted use syringes to deliver their insulin.

*Table 1. Details of participants involved in one-to-one study (Chapter IV)*

<b>Pseudonyms</b>	<b>Recruitment</b>	<b>Ethnicity</b>	<b>Marital Status</b>	<b>Children</b>	<b>Employment Status</b>	<b>Age at interview</b>	<b>Age when diagnosed</b>	<b>Details of Treatment Regimen</b>
Michael	Press Release	White English	Single	None	Retired	60	6	2 Bovine Insulin injections daily (delivered by syringe)
Ted	Press Release	White English	Single	None	Retired	50	25	2 Mixed–Insulin injections daily (delivered by syringe)
Brian	Press Release	White English	Married	Partner pregnant with first child at time of interview	Employed	36	2	4 Insulin injections daily (delivered by insulin pen)
Darren	Press Release	White English	In a relationship	None	Student	22	4	4 Insulin injections daily (delivered by insulin pen)
Anthony	Snowball	White Irish	Married	None	Employed	34	15	4 Insulin injections daily (delivered by insulin pen)
Ben	Snowball	White Irish	Married	1 daughter	Employed	36	32	4 Insulin injections daily

								(delivered by insulin pen)
Paul	Snowball	White Irish	Married	3 children	Employed	45	20	4 Insulin injections daily (delivered by insulin pen)
Liam	Snowball	White Irish	Married	1 son	Employed	27	27	4 Insulin injections daily (delivered by insulin pen)
Martin	Press Release	White English	Married	2 children	Retired	68	52 <sup>1</sup>	4 Insulin injections daily (delivered by insulin pen)
Conor	Snowball	White Irish	Single	None	Student	18	10	4 Insulin injections daily (delivered by insulin pen)
Shane	Snowball	White Irish	In Relationship	None	Employed	24	6	4 Insulin injections daily (delivered by insulin pen)
Aiden	Snowball	White Irish	Married	None	Retired	71	25	4 Insulin injections daily (delivered by insulin pen)
James	Snowball	White Irish	Married	1 daughter	Employed	37	5	4 Insulin

<sup>1</sup> While a diagnosis of Type 1 diabetes at 52 is rare, Type 1 diabetes can occur at any age.

								injections daily (delivered by insulin pen)
Glenn	Snowball	White Irish	Married	2 children	Employed	36	9	4 Insulin injections daily (delivered by insulin pen)
Pat	Snowball	White English	Married	2 children	Employed	55	8	4 Insulin injections daily (delivered by insulin pen)

Recruitment to the empirical study detailed in Chapter VI followed a similar approach. Ten couples were recruited as participants to the study. All couples were observed to be heterosexual, although it was not necessarily an aim of the research to attend solely to the experience of heterosexual couples. Of the fifteen men that took part in the first study (Chapter IV), seven agreed to take part in this study along with their partners. The remaining three couples were recruited through snowball sampling. In the case of one of the couples, both partners had Type 1 diabetes. Table 2 presents details regarding each of the couples, including information about the number of children they have, how long they have been in a relationship, and any diabetes-related complications they may have. All participants were either White Irish or White English. There were no requirements on length of time diagnosed with diabetes.



*Table 2. Details of participants involved in couple's study (Chapter VI)*

<b>Pseudonyms</b>	<b>Recruitment</b>	<b>Ethnicity</b>	<b>Ages</b>	<b>Length of relationship</b>	<b>Details of children</b>	<b>Duration of diagnosis</b>	<b>Details of Complications</b>
Jack and Clare [both have Type 1 diabetes]	Snowball	Both White English	Jack 58 years; Clare 52 years	33 years	2 adult children: 1 male, 1 female; male also Type 1	Jack 40 years; Clare 42 yrs.	Jack: eye problems; stomach problems; no feeling in legs (confined to wheelchair). Clare: eye problems; no feeling in toes. (also suffers with IBS).
Brian and Louise	Study 1	Both White English	Brian 36 years; Louise 35 years	8 years	1 son, 8 weeks old (present at interview)	34 years	Starting to show signs of eye problems (no medical intervention required yet); some issues with kidneys (on life-long medication for this).
Glenn and Deirdre	Study 1	Both White Irish	Glenn 36 years; Deirdre 38 years.	12 years	2 daughters under 4 years (present at	27 years	Early signs of eye complications

					interview)		
Martin and Kate	Study 1	Both White English	Martin 68 years and Kate 67 years	47 years	2 adult children	16 years	None
James and Glenda	Study 1	Both White Irish	Both 37 years	15 years	1 daughter, 12 weeks old (present at interview)	32 years	None
Liam and Aoife	Study 1	Both White Irish	Both 27 years	3 years	1 son, 18 months old.	8 months	None
Aiden and Caroline	Study 1	Both White Irish	Aiden 71 years; Caroline 70 years	49 years	None	46 years	None
Ben and Fiona	Study 1	Both White Irish	Ben 36 years; Fiona 34 years	5 years	1 daughter, 6 months old	4 years	None but also suffers from epilepsy
Ken and Emma	Snowball	Both White English	Ken 36 years; Emma 33 years	8 years	None	18 years	None
John and Denise	Snowball	Both White English	John 27 years; Denise 21 years	1 year	John has 4year old daughter from previous relationship	21 years	Sexual dysfunction and early indications of retinopathy

### *3.3.2 Data Collection – Online Study (Chapter V)*

Initially, I carried out an internet search for online forums relating to diabetes (both Type 1 and Type 2) and found the majority of sites available were open to both men and women. The use of usernames, and absence of additional information about the site-users, made it very difficult to confirm the gender of the posters. A further difficulty associated with these sites, was the breadth of topics discussed on the forums. For example, one popular diabetes website, with 30,834 members, offers 20 different forums to its members including, for example, 'Insulin Pump Users Forum' and 'Continuous Glucose Monitoring Forum'. The 'Type 1 Diabetes Forum' of this particular website has 5,124 discussion topics. I felt that the task of reviewing such an amount of data was far greater than permitted by the timeframe of my research. In order to establish parameters for my search, I kept the focus of my research close to mind. As I was concerned with men's experience of diabetes, I was forced to narrow my focus to those sites which provided a specific area for men with the disease to post. This brought me to a US-based website which operated a 'Men's Corner' under the 'Sex and Intimacy' section of their website. This website acts as an online diabetes community with 74,601 members. It provides users with dietary information, latest developments in diabetes research, and the opportunity to interact with other diabetics through their online forum, live chat facilities and blogs.

Whilst it is predominantly men who post on this forum, women also provide comments and suggestions – many of whom also have diabetes, or are in a relationship with someone who has the disease. At the time of write-up, there are 82 threads in this forum. The majority of postings on the forum relate to the topic of sexual-dysfunction (64 of 82) with erectile-dysfunction (ED) receiving most discussion. Other issues such as how men carry their diabetes equipment, and details about new insulin treatments are also discussed but to a considerably lesser degree. For this reason, the analysis focused exclusively on postings regarding ED. The threads on the forum appear in order of popularity, rather than chronologically. The popularity of a post is determined by the number of views it has received. This is updated automatically, as soon as someone views the post. I selected the ten most popular threads, as determined by the website, which dealt with the issues of ED. I argue that by selecting the most popular postings, I am attending to the topics most

relevant to the majority of men with diabetes who use this website. The final data-set consisted of 122 postings.

It should be noted that both men with Type 1 diabetes and men with Type 2 diabetes utilise this forum. As such, the analysis and discussion presented here are based on the accounts of men from both of these illness groups. While Type 1 diabetes and Type 2 diabetes vary in their aetiology and treatment, they share the same potential complications. Therefore, while the rest of this thesis focuses solely on men with Type 1 diabetes, I argue that the inclusion of men with Type 2 diabetes here, in an empirical chapter which is concerned with a specific complication of diabetes, does not problematize this focus. An additional point of note regarding this sample is that of geographic location. As stated, the online forum used in this research is situated within a US-based website. As such, the forum is available for use globally. There is a wide variety in the geographic location of posters to this forum – ranging from the US to Europe. This variation is reflected in the postings as grammatical and syntactical errors are evident which may suggest that English is not the first language of the author. More importantly perhaps, is that this geographic variation (both within this sample and compared to the participant samples of the other empirical chapters of this thesis) brings with it experiences of different health services. The availability of treatment for both diabetes and ED may vary from country to country (for example, diabetes medication is free through the NHS in the UK whereas access to such medicine in the US is determined by level of health insurance). Culture may also play a role in the extent to which individuals disclose online, thus the cultural diversity of this group must be acknowledged.

One of the challenges of this type of observational internet mediated research is determining the sex of the forum user. To this end, each poster's 'bio' served as an aid. The 'bio' contains information about the forum user such as, sex, the type of diabetes they have and the medication they use, the number of complications they have, etc. Forum users vary in the amount of information they include in their 'bio' and in the absence of such information, postings were only used if the sex of the individual was clearly discernible from the content of the post, for example postings which contained an account of trying to restore erectile-functioning and concerns for one's wife were taken as coming from a male whilst other postings which referred to

'my husband' or 'we women' were taken as coming from a female.

### 3.3.3 *Semi-structured Interviews*

I wanted the interviews to provide participants with the opportunity to discuss their 'diabetic-story'. In keeping with the principles of grounded theory, I kept the interview questions broad and open-ended. I allowed participant's accounts to direct the flow of the interviews. However, in order to ensure the interview produced 'in-depth' data, I often 'probed' particular statements by asking 'can you tell me more about that?' or 'how did you feel about that' to 'encourage reflection and introspection about particular issues, events, and experiences' (Olliffe & Mróz, 2005).

Participants often stated that they felt comfortable speaking with me about their situation as I had my own personal understanding of what it is like to live with diabetes. Furthermore, participants did not need to explain 'diabetes-jargon' to me (for example, when a participant spoke about their HaA1c levels, I was already aware that this referred to their glycelated haemoglobin levels which is the medical yardstick used to determine an individual's blood-glucose control over an eight week period). This shared knowledge meant that the interview could flow without being interrupted in order to explain diabetes terms. At the same time, I was cautious not to lead participants by sharing too much of my personal experience. Disclosures about my diabetes were generally made in order to establish a rapport with participants and build the interaction as a conversation rather than a formal interview. While my commonality with my participants was certainly an asset to the research, it was sometimes challenging to meet people who were suffering with severe diabetes-related complications. The support of my supervisory team, and the reassurance received through my own health check-ups were beneficial at such times.

As stated, in the Introduction to this thesis (Chapter I), I was interested in learning about men's *holistic* experience of living with diabetes. By *holistic*, I refer to the entire impact of diabetes on life. While this includes blood-glucose testing, dietary management, hospital check-ups, bouts of low and high blood-glucose levels, and confronting diabetes-related complications, it also encompasses the psychological and emotional energy spent on diabetes. As someone with the disease, I view

diabetes as being with me all of the time. I live with it every moment of every day and will continue to do so for the rest of my life. As the years since my diagnosis progress, I often contemplate what my 'diabetic future' will bring; will I suffer with the major complications associated with the disease? If I have children, will they develop diabetes? Will I be cured? It is this sense of uncertainty that, for me, is the most difficult aspect of living with diabetes. When designing the interview schedule for the empirical study detailed in Chapter IV, I wanted to allow scope for my research participants to talk about *all* the ways in which diabetes affected their lives and how living with diabetes made them feel. I also wanted to attend to the *chronic* and life-long nature of the disease. To this end, I drew up an interview-schedule which was divided into four sections: 'Diagnosis', 'Impact of illness', 'Feelings towards diabetes' and 'Past, present, and future'. The aim of the interview was that participants could take me on their diabetic-journey from their initial diagnosis to the present day, re-visiting important life-transitions along the way and culminating with the contemplation of what their future will bring. For example, a number of questions focused on the reaction to diagnosis and how diabetes was immediately incorporated into life, while periods of transition (moving to university, getting married etc.) were also considered including how these changes affected the relationship with diabetes. Each interview concluded with discussion of how satisfied one is with their current relationship with diabetes and how they view their future in light of this relationship. In addition to these topics, participants were free to discuss anything that they felt was relevant to their experience of diabetes. These one-to-one interviews were carried out with the participants, either in their own homes or on university premises. The interviews ranged from between 30 minutes to 2 hours in length (mean: 1hr 15mins) and were audio-recorded. The interview-schedule can be viewed in Appendix A.

Referring to the work of Cort, Monroe and Oliviere (2004), Taylor and de Vocht (2011) argue that 'it is important not to exclude the partner when studying the effects of a life-threatening illness, because the coupled relationship will influence how the course of illness is negotiated' (Taylor & de Vocht, p. 1577). While Type 1 diabetes may be classified as a chronic rather than life-threatening illness, the literature considered in Chapter II would suggest that the impact of living with Type 1 diabetes goes beyond that of the ill person, to affect those close to him/her. I was

interested in hearing from couples who co-exist in the presence of Type 1 diabetes and in establishing how they negotiate life with diabetes together. While one-to-one interviews were used in order to explore men's experience as individuals affected by Type 1 diabetes (Chapter IV), the inclusion of men's partners in the study detailed in Chapter VI facilitated an understanding of 'the collective perspective of the couple' (Taylor & de Vocht, 2011, p. 1578).

I became personally interested in the couple's experience of illness after reading a post on an online diabetes forum a number of years ago. This posting read '*nobody knows what it is like to live with diabetes until you have it*', to which the partner of a person with diabetes responded '*well you don't know what it is like to live with someone who has diabetes*'. Prior to this, I had never considered that *my* diabetes may affect the lives of those around me. I was interested to know if other people with diabetes had thought about this and particularly men with diabetes, given the traditional role of women as carers. I was also interested in hearing how the partner's experience of diabetic life has evolved over time. To this end, I designed an interview schedule (see Appendix B) which, similar to that for Chapter IV, aimed to capture the chronicity of the disease by asking questions about, for example, how the roles in diabetes-management have changed over time and how the couple feel about the presence of diabetes in their lives. Semi-structured interviews were carried out with the couples in their own homes. The interviews ranged in length from 1 hour to 1 hour 40 minutes (mean: 1 hour 26 minutes) and were audio-recorded. At the beginning of each interview the couple completed a form which asked them for details regarding the length of their relationship, the number of children they had, the duration of diabetes diagnosis and details of any diabetes-related complications (see Appendix C). This background information enabled me to tailor some of the questioning to the specific experience of the couple. For example, if the diagnosis of diabetes came after the couple had met, I asked the partner how she reacted to the diagnosis, while in the cases of men who were diagnosed prior to meeting their partner, I asked the male partner how he felt in the build-up to disclosing his diagnosis to his new partner for the first time. In a similar approach to the one-to-one study detailed in Chapter IV, the aim of the questioning was to gain an understanding of how both partners have experienced life with diabetes from the initial diagnosis or start of the relationship, to the present. A number of questions

focused on how diabetes is managed and the roles assumed by each partner regarding diabetes care. How these roles have changed over time was also discussed, as were the couples' feelings towards the presence of diabetes in their lives. All participants were given the opportunity to view the interview schedule prior to participation in the study. They were free to stop the interview at any time and to withdraw their data from the study. Details of sources of support were given to all participants after completion of the interview (Appendix D).

All men who participated in the one-to-one study (detailed in Chapter IV), were invited, along with their partners, to participate in the couple's study (Chapter VI). Seven of these men, and their partners, agreed to do so. I acknowledge it may be the case that for these participants, the couple's interview offered the opportunity to discuss topics which became relevant to them on reflection of their participation in the one-to-one interview. It may also have had the effect of priming couples as the male partner may have assumed that the topics discussed in our one-to-one interviews would receive further examination in the couple's interview. The overlap between the samples for these studies lends itself to further analyses of the individual versus shared experience of living with Type 1 diabetes. However, such analyses were beyond the remit of this thesis.

### *3.3.4 Gender dynamics of interviewing*

Citing the work of Hyman et al. (1954) and Carli (1991), Herod (1993) argues that 'an interviewer's gender can significantly influence an interviewee's responses to questions, at least pertaining to certain topics' (p. 308). Moreover, as the interview represents a dynamic interaction between interviewer and interviewee, the gender of the interviewee may also influence the discussion of certain topics. In relation to interviews with men specifically, Broom, Hand and Tovey (2009) argue that 'pressures to enact cultural ideals of masculinity (whether in the context of female or male interviewers) may function to 'cover-up' key issues faced by men' (p. 54), citing the example of 'impotence or incontinence' in the case of men who have experienced prostate-cancer.

My biography as a young female with Type 1 diabetes both served to establish a



commonality with my participants and a gender-based distinction. I was part of the 'diabetic-group' within which my participants were situated, and for the most part, this position encouraged openness in men's accounts. However, it may also be the case that my gender inhibited the discussion of certain topics. For example, during the one-to-one interviews (Chapter IV), I asked all participants to tell me about diabetes-related complications they may have experienced. I never specifically asked about the occurrence of erectile-dysfunction, yet three participants immediately spoke about their experience of this complication whereas the others did not. Indeed one of the participants response was, 'I presume you mean impotence', indicating an expectation that this is what I would be interested in given my focus on men's experience of diabetes. When I explained he could discuss any complication he wished he added, 'I don't want to cover something you're uncomfortable with', a consideration that may not have been given if the interviewer was male. In the case of the participants who did not discuss sexual-functioning, it may be the case that they did not have experience of this complication, or that they did not feel comfortable discussing it with a female researcher. The accounts of sexual-dysfunction which were shared were very detailed. These men explained to me the nature of the dysfunction (erectile-dysfunction in the case of two participants, and retrograde ejaculation in the case of another), the medical-interventions they have tried, and their feelings of loss resulting from their inability to have children.

Broom et al. (2009) noted that in interviews undertaken by a male researcher, male interviewee's 'attempted to reinforce, or indeed perform, dominant constructions of masculinity through language and rhetorical practices which conveyed certain cultural understandings about men's sexual practices' (p. 58). Such 'cultural understandings' regarding sexual practices were, for the most part, absent from my participant's accounts. Instead, the accounts were marked by feelings of loss, and sex was presented as something which should be 'special', 'caring', and should 'mean something'. Given these observations, I have been mindful of my position as a female researcher and of the possible implications of this for the developing analyses.

### *3.3.5 Ethical Considerations – Chapter IV and Chapter VI*

Each of the empirical studies of this thesis was carried out in accordance with the ethical guidelines of the British Psychological Association and ethical approval was obtained from Nottingham Trent University. In the case of the one-to-one study and the couples' study (Chapters IV and VI respectively), participants were given the opportunity to discuss the nature of the research, and any other questions they may have had, prior to agreeing to take part. They were also afforded the opportunity to view the interview schedule in advance and indicate if there were any particular topics they would prefer not to talk about. Participants were also made aware that they were free to terminate the interview at any time, and could decline to discuss any topics during the course of the interview. Furthermore, they were made aware of their entitlement to withdraw their data from the study within three months of completion of the interview. Additional information about the nature of the research was also supplied to the participants prior to obtaining their consent to participate (see Appendix E and Appendix F). I informed them of the efforts I would take to protect their anonymity (by assigning a pseudonym to the data and by removing any potentially identifiable information). Participants were also made aware of the fact that their data would appear in this thesis and may also be used in conference papers and other publications. Once all of this information was explained to the participant, signed consent was obtained (see Appendix G). Following completion of the interviews, I reminded participants of their right to withdraw their data from the study, within the time-frame, and I also provided them with a de-brief sheet (see Appendix D) which provided my contact details and the contact details of my Director of Studies. This sheet also supplied contact information for a number of support-groups and diabetes-related resources which may be of assistance to participants should they feel concerned about some of the issues raised in the interview. None of the participants asked for their data to be withdrawn from the study. None of the participants received payment of any kind for their participation.

All participants had been informed that I was also living with Type 1 diabetes and a number of participants commented that this made it easier to talk about their situation. In some cases, particularly when I felt the participant was a little hesitant to open up about a particular topic, I would share some of my own experiences of

diabetic life and the interview would often proceed in a conversational style with each exchange from me being reciprocated by the participant with details of their personal experience. Whilst it is felt this shared diagnosis did assist within the recruitment process and the interview setting, I was cautious of leading participants and so tried not to disclose too much detail of my personal experience. My dual position of interviewer and fellow-diabetic was personally challenging when I encountered participants who had experienced severe diabetes-related complications. I found that regular meetings and discussions with my supervisory team helped to alleviate my concerns. In the case of the interviews I conducted with couples, there were occasions when I felt that my diagnosis, and perhaps my status as researcher, caused female partners to treat me as an authority on the subject of diabetes. Often I was asked about the recent advances in treatments or the truthfulness of their partners' claims regarding the symptoms of hypoglycaemia or 'moodiness' caused by hyperglycaemia. I was always careful to declare my opinions as based on my own experience rather than any greater expertise on the subject. I also tried to use partner's questions as cues to discussions between the partners.

### *3.3.6. Ethical Considerations – Chapter V*

As in the case of Chapters IV and VI, this study was carried out in accordance with the ethical guidelines of the British Psychological Association and ethical approval was obtained from Nottingham Trent University.

While it is necessary to become a member of the forum in order to post comments, non-members (i.e. the general public) are able to view the postings without any obligation to join the online community. The postings, therefore, exist in a public and open sphere. I did not join this online community, rather I 'harvested' the postings which were publicly available. Indeed there appears to be an awareness amongst the users of the forum that their postings are publicly viewable. This is evident when posters make reference to 'PM'. This refers to a 'private message' facility in which users of the website can communicate with each other in a private manner which is only viewable to those included in the PM (similar to email). The decision to post to the forum (as opposed to through PM), represents an acceptance that postings are public. As such, (and given the fact that I have not interacted with

the users of the forum in any way) I have treated these postings as public and I do not deem it necessary to obtain consent from the users of the forum to use the postings in my research. This is consistent with the recommendations of Rodham and Gavin (2006) who argue that 'as long as researchers maintain the confidentiality of the individuals who have 'posted' and record data in a manner that would not cause personal identification, it is not necessary to seek consent of individuals using open message boards because ethical boundaries are not crossed' (p.94-95). That said, I did contact the owner of the website to advise him of my study and ask his permission to use the postings from the forum. I explained that, should he agree, these postings may appear in my thesis and in any future public. The owner kindly agreed.

Safeguarding the confidentiality and anonymity of users of forums is not a straightforward task. While people who post to a forum do so using a self-appointed username, this username may indeed bear some resemblance to their own name. While I have taken efforts to replace all usernames with a pseudonym (and disguise any other identifying information in the postings), there is nothing to prevent the linkage of the extracts I have quoted with their original poster by entering the extract in an internet search engine. While some researchers would recommend that to overcome this problem the quoted text should be altered (Kraut et al., 2004), I have chosen not to do so in order to preserve the context in which the text is situated (as emphasised by Charmaz, 2006). Should the quoted extracts be linked back to their original poster, this serves to demonstrate further the public nature of the data.

### **3.4 Data Analysis**

In this section I detail my approach to data analysis, using grounded theory techniques.

#### *3.4.1 Line-by-line Coding*

The initial stage of analysis of data in a grounded theory study is known as 'coding'. Here the researcher engages closely with the data and assigns codes to each line of the data or incident of an event in the data. Corbin and Strauss (2008) advise that

coding 'requires searching for the right word or two that best describe conceptually what the researcher believes is indicated by the data' (p.160). While various coding techniques exist (e.g. word-by-word coding, line-by-line coding, and incident-to-incident coding, axial coding, focused coding, and selective coding), I opted for line-by-line coding in my analysis. Willig (2001) argues that line-by-line coding is necessary when the abbreviated version of GT is being used, as the 'depth of analysis generated by line-by-line coding is needed to compensate for the loss of breadth that accompanies the researcher's dependence upon the original data set' (p. 38). Line-by-line coding involves naming each line of the data. To this end, I divided each interview transcript, or forum-posting, into two columns. The data was pasted into the left-column and the code for each line written in the corresponding space on the right-column. I have included an example of coding in Table 3 (below). As recommended by Charmaz (2006) I kept the codes 'active' and used the following guide, as suggested by Charmaz (2006), to aid the process (taken from Charmaz, 2006, p. 49):

- ⤴ Remain open
- ⤴ Stay close to the data
- ⤴ Keep your codes simple and precise
- ⤴ Construct short codes
- ⤴ Preserve actions
- ⤴ Compare data with data
- ⤴ Move quickly through the data

A major advantage of this type of coding is that it requires very close interaction with the data and therefore minimises the potential for researchers to impose their own views or expectations on the data. As Charmaz (2006) states it 'helps you to refrain from imputing your motives, fears, or unresolved personal issues to your respondents and to your collected data' (p.54). My closeness to this subject area meant that such careful coding was important to ensure that I did not allow my own experiences to guide the analysis.

***Table.1 Example of coding taken from Study 1- interview with 'Darren'***

<b>I: Yeah, did you have</b>	
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<p><b>to tell your new friends what to do if something goes wrong and you have a hypo?</b></p> <p>D: Em I didn't really tell them what to do, I told them I was diabetic cos obviously when we'd eat together I'd have to inject myself, em you have to explain that and em, I guess I just assumed they'd ring for an ambulance or I I'd feel rather silly explaining to people what they should do if I, fail, kind of thing. I know it sounds a bit daft.</p> <p><b>I: Well would you see it as...when you say 'fail' what do you mean?</b></p> <p>D: Em, well it's like I've messed up, I've done something wrong</p>	<p>Levels of disclosing</p> <p>Feeling a social expectation to explain injections - disclosing to avoid stigma.</p> <p>Vaguely concerned by health implications of disclosure</p> <p>Picking up the pieces</p> <p>Feeling like a failure – hypos indicative of personal mistake</p>
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In this example, Darren explains how he arrives at telling his friends that he has diabetes. The coding I used here primarily consisted of active words which aimed to

describe what the participant was *doing* in each line of the transcript. By coding the entire interview-transcript in this way, I accumulated a list of codes which represented the threads by which an unstructured account of living with diabetes could be pulled together. I set about examining the similarities and differences between codes, and grouped codes together based on their likeness.

### *3.4.2 Clusters, concepts and categories*

Coding can be viewed as a means of breaking the data down into analytic chunks. The subsequent grouping of similar codes into categories is the first step in piecing the analytic story together. Categories are formed by grouping similar codes together. In doing so, the researcher specifies 'its properties, notes the conditions under which it arises, relates how it changes, describes its consequences, and ultimately, specifies its relationship to the other conceptual categories' (Charmaz, 1990, p. 1168).

The grouping of similar codes is referred to as clustering. During this process, I examined the similarities and distinctions between codes. I identified a main cluster (in the case above, Disclosure could be viewed as the main cluster) and grouped all other codes relating to this topic under this cluster. By examining the relationships between these codes I was able to draw out sub-clusters (for example 'Reasons for Disclosing'). I repeated this process until I had developed a set of clusters and sub-clusters which accounted for all of the transcript's codes. In the same way as I had dealt with the grouping of codes, I then moved on to examine the relationships between the clusters, noting the elements that made each cluster distinctive and also the commonalities between clusters. I proceeded to group similar clusters together to make concepts. For example, the cluster 'Disclosure' was grouped with the cluster 'Facing change' to become part of the concept 'Managing Transitions'. This process of making constant comparisons was continued through to the next stage of the analysis where concepts were grouped together to form categories. In this case the concepts of, for example 'Managing Transitions' and 'Recognising Mortality' were grouped to form the category 'Reassessing the relationship with diabetes'.

### 3.4.3 *Constant comparative analysis and Memo-writing*

The progression from codes to conceptual categories is aided by a method of constant comparative analysis and also with the aid of memo-writing. 'The constant comparative method is what holds together the iterative analytical process in grounded theory' (Weed, 2009, p. 506). Throughout the studies, I made comparisons during each stage of the analysis; comparing codes with codes, categories with categories and the emergent theory with the existing literature.

As advocated by Glaser and Strauss (1967) and also Charmaz (2006), memo-writing played an integral part in both the development of the analyses and in the final write-up of each study. I utilised a 'freewriting' approach to memo-writing. I was unconcerned by sentence structures or grammatical errors and instead focused on keeping track of my thoughts regarding the emerging analysis. I used memos to note tentative links between concepts and categories and to keep track of my ideas regarding the direction of the analysis. For example, in the early stages of coding Study 3 (Chapter VI), I recorded my thoughts about the emerging analysis in a memo. At this early stage, I noticed that issues of 'equality' were dealt with by some of the couples. I noted that 'equality' could account for the female partner's decision to adopt the same diet as their diabetic partner, but it could also account for their resistance to assuming the responsibilities of carer. Also in this memo I wrote 'sharing the burden of disease' and thought about the parallels which could be drawn between other couples and disease-groups. This memo served as a prompt for when I returned to the literature after completion of the analysis.

### 3.4.4 *'Theoretical' Saturation*

In the absence of *theoretical sampling*, I cautiously claim 'theoretical saturation' as a significant stage in the development of my analysis. Charmaz (2006) explains theoretical saturation as: '[c]ategories are 'saturated' when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories' (p. 113). In traditional grounded theory research, theoretical saturation is the point at which one would stop collecting new data. In the case of, for example, Chapter IV of this thesis, I worked through the first ten transcripts



elevating codes to concepts and built up an understanding of the general terms of each category. I then proceeded to code the final five transcripts and examined how these new codes related to the working framework I had developed (whilst also remaining open to new directions in the data). The patterns I found in the final five transcripts could be accounted for by the codes and categories established following analysis of the earlier transcripts. At this point, I was confident that my data-set supported the developing theory, whilst also providing sufficient variation, or *negative cases*, to allow for delineation of the categories.

### **3.5 Analysis of Online Data using GT**

Charmaz (2006) includes internet discussions as an example of extant texts in which the researcher does not influence the construction of the text. Such texts may give insights into 'perspectives, practices, and events not easily obtained through other qualitative methods' (p. 39). The study detailed in Chapter V followed the procedure detailed above in its grounded theory analysis of postings to a diabetes forum.

When using postings from online discussion boards, Charmaz (2006) emphasises the importance of situating the texts in their contexts. To this end, the extracts presented in Chapter V are presented in the order they appeared on a 'thread' in an attempt to illustrate the exchange taking place online between posters. All extracts are presented as they appeared on the forum inclusive of any spelling or grammatical errors. Details of the number of times each posting has been viewed and the number of replies to each posting are also included with each extract in order to give the reader an insight into the popularity of the posting. In an attempt to protect anonymity, usernames have been changed, and any other potentially identifiable information has been omitted.

### **3.6 Assessing the quality of my GT approach**

As Charmaz (2006) states '[the] quality – and credibility – of your study starts with the data' (p. 18). As I was interested in men's experience of living with Type 1 diabetes, I strove to keep the data-set as broad as possible, thereby ensuring a variation in age, duration of diagnosis, and perspectives on disease-management. I

engaged in purposeful sampling with a view to recruiting participants from a spread of age ranges. Recruitment was designed to provide a good spread of ages and this was achieved by ensuring there was at least one participant within each ten-year bracket (e.g. 20-30, 30-40, 40-50, and so on). This spread of ages provided an insight into the lived experience of diabetic men at varying life-stages, having experienced different forms of treatments and advancements in care. The variation in the number of years diagnosed with diabetes resulted in variations in the physical health of the participants which in turn added to the breadth of understanding of diabetic-life. Additionally, by recruiting through snowball sampling and press-releases, as opposed to through diabetes-clinics, I was able to engage with men who had fallen away from their health-care provider along with those who consistently attend their medical appointments. As recommended by Charmaz (2006), I obtained through the interviews, a detailed description of my participants' views and any changes in these views over time, alongside the background information to add to my understanding of these views.

Inherent in the GT method I have used are a number of quality checks which serve to limit the intrusion of researcher subjectivity and ensure that the theory is truly grounded in the data.

In the case of each of the empirical studies, I delayed the literature review until after completion of the analysis. Glaser and Strauss (1967) advised researchers to 'literally ignore the literature of theory and fact on the area under study, in order to assure that the emergence of categories will not be contaminated by concepts more suited to different areas. Similarities and convergences with the literature can be established after the analytic core of categories has emerged' (p. 37). While I had a prior knowledge of the qualitative research in the area of diabetes (from my previous study and personal interest in the area), I did not carry out an examination of literature into, for example, men's adjustment to chronic illness, the couple's experience of diabetes, or the use of online forums by men with diabetes until after completion of the analysis in each empirical chapter.

It is impossible, of course, to come to study a particular subject with no prior knowledge of it (particularly in the case of this thesis) and so the strategy of line-by-

line coding helped to control the influence of my prior knowledge by focussing my close attention on the data. Dey (1999) advises that 'there is a difference between an open mind and an empty head' (p. 251) and researchers should remain open-minded when coding so our prior knowledge does not close our minds to new ideas. Indeed (Charmaz, 2006) described line-by-line coding as an 'early corrective' to 'reduce the likelihood that researchers merely superimpose their preconceived notions on the data' (p. 51).

My use of memos and constant comparative analysis acts as a further correctives to ensure the quality of my GT approach. Memos are used as a means of sensitizing the researcher to his/her own personal biases during the research which in turn serves to control the quality of the data analysis (Elliott & Lazenbatt, 2004). Additionally, the constant checking (through the use of constant comparative analysis of codes, categories and memos) forced me to keep focused on the data. The use of memos and the constant comparative method, along with line-by-line coding and delaying the literature review, enabled me to limit the intrusion of *a priori* assumptions on the development of the studies. Indeed the use of these methods, alongside theoretical sampling, are recommended as the criteria by which the quality of GT research is assessed (Elliott & Lazenbatt, 2004).

The quality of this research is further discussed in the Discussion Chapter of this thesis (Chapter VII), where I apply Charmaz (2006), criteria for grounded theory studies to the work presented in this thesis. This criteria assesses the *credibility*, *originality*, *resonance*, and *usefulness* of the research.

### **3.7 Summary**

This chapter has provided a brief introduction to the principles of the Grounded Theory methodology and explained the methodological approach used in this thesis. I have detailed how this approach has been incorporated into each of the empirical studies. I have argued the suitability of grounded theory as a method, given its recognition of the personal perspective of the researcher and the quality checks inherent in the method which serve to limit the intrusion of this perspective on the analytic process. The suitability of GT has further been evidenced with reference to

its prevalence in the field of health-related research.

## **Ch. IV: *'It's not a disease, it's a nuisance'*: Controlling diabetes and achieving goals in the context of men with Type 1 diabetes.**

### **4.0 Introduction**

In the previous chapter, I detailed the methodological approach employed in this thesis, namely an abbreviated version of grounded theory, particularly informed by the work of Charmaz (1983, 1990 & 2006). In the current chapter I report on an interview-based study I conducted with fifteen men, all of whom had Type 1 diabetes. Using the methodology detailed in Chapter III, I discuss the findings and implications of this study.

As the literature reviewed in Chapter 2 illustrates, there is a paucity of research into men with diabetes. The research which does exist is primarily situated within a biomedical framework. In addition to a focus on sexual-functioning (evidenced in Chapter 2), several researchers have explored the relationship between testosterone levels and diabetes (e.g. Grossmann, 2011; Dhinda, S. et al. 2011; & Jones et al. 2011), and the interaction between cardiovascular disease and diabetes (Pries et al., 2009; Dagenais et al., 2009; & Wannamethee, Shaper, & Walker, 2005).

Consistent with the focus of mainstream health psychology research, men's self-management of diabetes has also received attention. This field of research focuses on the interaction of specific factors with diabetes self-management. For example, how ethnicity informs men's management of diabetes has been looked at by Jack et al. (2010) in their study of black men with diabetes in the United States. Their research points to a lack of consideration for how attributes of masculinity influence how men within this ethnic group manage their diabetes. Rustveld et al. (2009) have looked at the particular self-management practices of English- and Spanish- speaking Hispanic men. They highlighted a particular reluctance amongst members of this group, to change culturally rooted practices (particularly in relation to traditional Hispanic food), despite healthcare recommendations.

While these studies examined a particular aspect of men's self-management of diabetes, very little research has explored the broader *lived experience* of men with

diabetes. Of the research that does exist into men and diabetes, the findings compliment some of the research into men with chronic illness in general, in which efforts are made by men to minimise the presence of diabetes in their lives. In Koch, Kralik and Taylor's (2000) study of men with Type 2 diabetes this was achieved through a process of 'normalization' in which diabetes is viewed as being a part of life and men adopt an individualized approach to diabetes care by experimenting with their lifestyles (Peyrot et al. 1988).

As Leonard (2004) argues, mens' perspectives of diabetes-related health issues 'have been either inadequately investigated or not investigated at all' and adds that 'health care providers can better respond to the needs of their male patients if they understand these patients' worldview' (Leonard, 2004, p. 206). With this in mind, this study sought to gain an understanding of what life is like for men with Type 1 diabetes using a grounded theory (GT) approach. I wanted to allow men the opportunity to share their experiences of life with diabetes without being confined to the parameters of a particular research question. As such, I designed this study with the broad question of 'what is it like to life with Type 1 diabetes?' in mind. The GT methodology facilitated this approach as it recommends that the researcher begin with a general research question which then narrows around the emerging analysis. Importantly, the GT method attends to the researcher's role throughout the research process. This was particularly important here as I also have Type 1 diabetes and thus came to the process of data collection and analysis with my own meanings and understanding of what life is like to live with Type 1 diabetes. In this chapter I shall detail the findings of this analysis and what these findings contribute to what we already know about men with diabetes.

#### **4.1 Analysis**

Following the analytic procedure detailed in Chapter 3, my analysis of the data identified an evolving process of adjustment to life with Type 1 diabetes, informed by the personal goals of the individual man with diabetes. Participants' engagement with the recommended diabetes-care regimen varied depending on their personal goals. While the term 'goals' was not explicitly referred to by participants, I employ it here to refer to the way in which one wants to live their life and what they want to

achieve in life. Three categories emerged from analysis of the data, these were: '*Reducing the seriousness of diabetes*'; '*Reaching goals and mis/managing illness*'; and '*Reassessing the relationship with diabetes*'. The core category was determined to be 'Controlling diabetes and achieving goals'; the process by which men's personal goals, rather than healthcare recommendations, informed the assimilation of diabetes into daily life.

#### ***4.1.1 Reducing the seriousness of diabetes***

One of the challenges when attaching a meaning or definition to diabetes, is that it is essentially a disease without a palpable presence. One can live each day without *physically* feeling that they are diabetic; the only reminders exist in the necessary insulin injections and blood-glucose tests (and side-effects of high or low blood-glucose levels). It is difficult, therefore, to define as an illness in the absence of feeling ill, as Shane explains:

*Shane: Age 24 years, diagnosed at 6 years. (line 313-318)*

**I: Do you think you will ever be cured?**

S: No. You have it for life but its not a massive disease. You can handle it.

**I: Do you think, how would you, you say its not a massive disease, do you look at it as a disease or an illness? What would you call it?**

S: Probably disease. I'm not really ill with it. Its, I have never missed school with it. Probably missed one day at the start with it. I've never been sick with it.

Whilst he knows that he will live with diabetes forever, being able to maintain normal life (and get to school everyday) leads Shane to reduce the seriousness of diabetes to 'not a massive disease'. Without the sensations of *ill-ness*, the seriousness of diabetes as a disease with the potential to disable, is often not spoken of by the participants in this study who have not experienced diabetes-related complications. Instead, diabetes is reduced to a frustration or a nuisance (Conor: *It's not a disease, it's a nuisance*); something which takes up time, requires extra planning and diverts

attention away from more important issues, as Liam suggests in this extract:

Liam: Age 27 years, diagnosed at 27 years. (line 121-122)

**Q: Do you see it as a lifelong illness?**

A: Not really no. Its not really that bad, its just annoying you know, the time it takes.

Here Liam's focus is on the time consumed by diabetes, rather than the fact that he will live with it for the rest of his life. The notion of diabetes as a 'lifelong illness' appears to suggest that it is a serious disease but Liam is quick to reject this; rather than viewing diabetes as 'bad', it is 'annoying'. With the outlook that 'it's not really that bad', it may be easier to justify a move away from doctor's advice and find a personalised way to live with diabetes – one which will, for some, minimise the length of 'time it takes'.

By reducing the seriousness of diabetes, the men in this study present a picture of the recommended care-regimen as being needlessly prohibitive, thus illustrating the often discordant views of patient and doctor. Brian (below) offers an appraisal of the recommended care-regimen as restrictive and tedious, and marked by a notable lack of progress. His appraisal also gives an insight into the often polarized views of patient and doctor referred to by the participants, with medical suggestions being rejected on the grounds of 'life being hard enough', and the ability to make an educated guess. The mastery and ability to achieve targets is confirmed by all of the men in this study, but as can be seen here, an assertion of ability does not guarantee action and for some, short-term quality of life is more important than the pursuit of 'normal' blood-glucose levels.

Brian: Age 36 years, diagnosed at 2 years. (line: 501-512)

B: but you can certainly tighten it up, whatever your situation is. I could do much better now frankly but life's hard enough as it is without me doing anything else.

**I: Do you feel that if you did try and tighten it up and follow all the strict guidelines that you'd actually be sacrificing quality of life because of it?**



B: Yeah, this is why I've never gone on the, what do you call the course they do?

**I: DAFNE\***

B: That's it, the doctor keeps saying that I should go on it but I I know from what I've read and from what other people have said about it, that it's heading back to what they did when I was two years old, and you get one potato and you measure the weight of it and you put it in to cook and you get your carrots, your peas, your corn, you measure it all, it's just, it's ridiculous and I I think if you're intelligent enough you can make a fair guess at how much to have

Similarly, Ted (below) refers to the restrictive nature of the care-regimen whilst also asserting his ability to reach blood-glucose targets, should he choose to. Here, Ted's decision to prioritize short-term quality of life is made in the knowledge that future physical health is being jeopardised.

*Ted: Age 50 years, diagnosed at 25 years. (line: 645–656)*

**I: do you feel that by having a higher A1c you're personally contributing to these complications or do you see it as just the diabetes that's causing it?**

T: No it's me, cos in an ideal world I can sit and I can eat absolutely to the letter and I can get absolutely 4 to 4.1 on the sugar-reading, so I have the ability to do that but like I say it would be such a miserable controlled existence you wouldn't put somebody through it that you hated, you have to have a little bit of slack on it well I, being weak-willed, going back to being a bloke again, give myself a bit too much slack occasionally that's all. But I'd rather do that and be able to do what I can while I can.

**I: So would you say that you control diabetes rather than diabetes controlling you?**

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\*Dose Adjustment for Normal Eating. This is a programme run by the NHS to enable people with diabetes to adjust their insulin dosages to complement the amount of carbohydrates they consume.

T: Yeah, like I say I'm not being beat, I mean I've got to accept that it won't go away, but, I can try and find a level where I can cope with it and not get too miserable or too aggravated about it.

The restrictive and oppressive nature of the regimen is emphasised with its potential to control and limit the ability and freedom of the person. Here Ted effectively constructs his account of following the regimen as what anybody would do – not just him. Having justified the decision to stray away from the regimen at times, Ted's subsequent attempts to maintain a healthy life-style are hindered by 'being a bloke' and allowing himself too much freedom. But this all forms part of finding the level where he can cope. He accepts that diabetes will never go away but he can fight its impact on his life by personalising his care-regimen to satisfy his individual needs and goals, rather than following the prescribed system.

In the extracts from both Brian and Ted (above), references to masculinity are evident in their appraisals of the diabetes-care regimen. Both assert their *ability* to reach the blood-glucose targets set out by their doctors. This possession of ability could be aligned to the traditionally masculine trait of mastery (Connell, 1995). However, Ted's association of 'being weak-willed' with 'being a bloke' goes against such hegemonic notions of what it is to be a man. It may be the case that 'being a bloke' holds a different set of masculine ideals of which allowing oneself 'a bit too much slack' is one. The personal culpability for non-adherence to the regimen is somewhat diminished by virtue that he is 'a bloke' and thus by nature 'weak-willed'.

There are variations between the men in this study with regard to how they choose to live with diabetes. For those like Ted, life should have minimal constraints or restrictions, and maximum freedom of choice. Ultimately, diabetes is required to 'fit' around, what I refer to as, personal goals. For many, the pursuit of personal goals and adherence to the recommended diabetes care-regimen are seen as mutually exclusive. Thus, reducing the seriousness of diabetes, gives license to move away from the recommended care-regimen and achieve such goals. For others, the pursuit of personal goals and attention to diabetic-health are interdependent, thus greater attention to health facilitates the achievement of such goals. As pointed out earlier, diabetes is a life-long disease and it would appear from my analysis, that the goals

one prioritised at the point of diagnosis may be different to those emphasised a number of years into diabetic life. Based on the reflections of the men in this study, as they contemplated their lives with diabetes from diagnosis to the present day, I would suggest that the way men live with diabetes is open to flux and change in response to their evolving personal circumstances.

#### ***4.1.2 Reaching goals and mis/managing illness***

Having established that personal goals influence the extent to which the diabetes care-regimen is assimilated into diabetic life, the next step in adjustment is to find a way to fit diabetes into life whilst at the same time striving towards the achievement of these goals. The analysis highlighted that priority is often attached to the personal goals of: the ability to work hard; and the responsibility of taking care of others. Whilst 'working hard' may be viewed as having traditionally masculine underpinnings (i.e. physical strength, breadwinner) (Connell, 1995), 'taking care of others' is more synonymous with traditionally feminine behaviour. This variation supports my statement in Chapter 2, that we must acknowledge the potential for the expression of multiple masculinities and various ways they interact with the management of chronic illness.

##### ***Working Hard***

The men in this study consistently attach importance to their role as breadwinner within the family. This role is uncompromisingly prioritized over the management of their diabetes, as the following extract from Liam illustrates.

*Liam: Age 27 years, diagnosed at 27 years. (line 26-35)*

**I: Could you not, where you work, could you not do it {test blood-glucose levels} there and then?**

L: No because if you are working you have to wash your hands, it's filthy. It's working on the walls, its freezing over there. On the job there's nowhere to wash your hands. It's all right now. Definitely not testing as much. Just once a day really. No, first thing in the morning and then before dinner in the evening.

**I: Is that just because it's not convenient at work?**

L: At work it's too busy, just too busy.

**I: So if you worked in a job that was different.**

L: Yes. I think if I was sitting in an office at a computer all day if you like it would be easier. My breaks aren't always the same.

The tough manual nature of Liam's work is, it would appear, incompatible with medical recommendations of frequent blood-glucose monitoring. His goals of being the breadwinner, getting the job done and keeping up with the pace of work means that he must compromise on diabetes management; as opposed to the recommended minimum of four BG tests a day, Liam manages to fit in two. There is a suggestion that other professions may allow for greater compliance with the care-regimen, for instance office-based jobs where breaks are at regular times, but for men doing 'men's work' the best fit for diabetes is outside of the working day – 'first thing in the morning and then before dinner in the evening'.

For others, like Anthony below, the desire to maintain a respected working reputation can sometimes result in diabetes being hidden from colleagues until such time that it cannot be disguised any longer. In Anthony's case, this disclosure came during an episode of hypoglycaemia in which he said or did 'something stupid' which he later was forced to explain as a feature of his disease.

Anthony: Age 34 years, diagnosed at 15 years. (line: 76-91)

A: I don't like talking about it really in normal run of the mill, daily routine.

**I: Like telling people what they need to do if something**

A: Especially the times I've made new friends or started new jobs, it's taken me a long time to tell people. It's a bad habit but I've only eventually told people when I've been forced into it. I might arrive into work and say or do something stupid and eventually come round.

**I: It's more like you get found out**

A: That's my own fault, it's a stupid thing to do. I feel that if you tell people you are diabetic, especially in the jobs I'm in,

engineering..[lines omitted]..If you told them you are diabetic they might think can he do the job...[lines omitted]...I didn't want people to assume I couldn't do something because I was diabetic. As far as I'm concerned there isn't anything I can't do.

For Anthony, reducing the visibility of diabetes, through non-disclosure, not only allows him to maintain a respected hard-working reputation, but also enables him to be viewed as 'normal' and capable of carrying out the same standard of work as his non-diabetic colleagues. He minimises the risk associated with non-disclosure by referring to it as 'a bad habit' while at the same time maximising his masculine ability by stating that 'there isn't anything I can't do'. This assertion of ability can be viewed as a performance of traditional masculinity. In this case, Anthony's dedication to work serves as a demonstration of his masculine identity, and protects against any threat that being 'a diabetic' poses to this identity.

When engagement in work, and the demonstration of masculine identity, is the goal of the individual with diabetes, rejection of their disease is sometimes necessitated. This is done despite the knowledge that it 'is a stupid thing to do' and, as James (below) states, there are better ways of managing it:

James: Aged 37 years, diagnosed at 5 years (lines 113-121)

J: when I'm doing something like that {building a fence} I want to keep going until it's done rather than letting someone down whereas if I stopped every hour and checked my sugar and prevented the hypos happening, that would be a better way of managing it

**I: and when you're doing a job like that, why do you want to keep pushing through, why don't you stop?**

J: it's just, especially if there's other people around, I don't like the idea of having to embarrass myself by saying I'm not able to do something they're able to do, so I don't like having to tell them, and they might be younger than me or they might be really inactive and overweight and if they're able to carry on and I'm quite healthy normally and I'm fairly slim, then I should be able to carry these

things through and be able to manage it.

James' engagement in physical labour (to the neglect of his diabetes) is driven by a sense of responsibility and pride. But these drives appear to be situational. While he is working, rather than 'let someone down', presumably by stopping to check his sugar-levels (which has the potential of delaying the speed of work), he powers through and runs the risk of hypoglycaemia. However in the context of the interview he is able to reflect on this behaviour and identify a better way of doing things. Similarly, a fear of appearing incapable when compared to others, who by their age or physique should be less capable than he, drives him to save face and avoid embarrassment. As a result he powers through and works as a man rather than as a diabetic. He holds the expectation of himself that if men who are overweight or unfit are able to do 'men's work', then so should he.

#### *Taking care of others*

Having seen how the traditionally masculine goal of working hard can impact negatively on diabetes-management, it would be easy to suggest that being a man is bad for your diabetic-health. However, the role of 'taking care of others', which was consistently observed in the accounts from the participants, illustrates how attention to health can be improved when one feels responsible for the welfare of others. This goal is presented here as an alternative expression of masculinity, moving away from the hegemonic ideal of 'working hard'. Indeed, the following extract from Ted would suggest that traditionally masculine behaviour is not conducive to good health:

*Ted: Age 50 years, diagnosed at 25 years. (line: 307-320)*

**I: So, you say you plan your own meals and you're quite good at managing meal-wise and following the advice**

T: yeah

**I: what's your motivation for doing that? Is it that**

T: eh cos I've got four pet birds that would die if I didn't, some days, other days cos I've got loads of other busy things to do but, like I say, we can all have miserable days and we think oh this is great and then come back to, there's folks that can't so you know,

you have to get over it. It doesn't mean that you sit comfortably with it at times but you get, you can carry on and you do think well I have got good friends, I wouldn't do that to them cos I had, I had a relationship that finished a couple of years ago after four years and it literally ran me into the ground. Talking about limitations again I was running, fetching, carrying, yeah you do that as a bloke to be old fashioned and, that's what you're supposed to do but hey, I'm out in the garden all the time I can spend sorting that out I don't even got a mug of tea done me

By aligning the typically masculine behaviours associated with hard-work, (running, fetching and carrying) with being 'old-fashioned' and detrimental to his health, Ted justifies his decision to change tack with regards to how he takes care of other people. These activities appear to be consistent with an established understanding of what 'blokes' are 'supposed to do'. However, for Ted, the elements required to preserve these activities were not available to him. Whilst taking care of his girlfriend, he became physically exhausted, yet never experienced a reciprocity of care from his partner. Now, with the benefit of these experiences, Ted achieves his goal of 'taking care of others' in a different way. In order to fulfil this role, he needs to be healthy or those depending on him will suffer; his pet birds would die or his friends would be let down.

However, pursuit of this role is far from easy. Ted depicts the changing nature of his engagement with diabetes, moving from a compliant health behaviour which is inspired by taking care of other people, to the days where he struggles to maintain such behaviour and relies on the attention of his dependants, and on those worse off than he, to pull him through. In addition to this, Ted underlines his determination not to become a burden on other people – as this would move him from the position of carer to dependant.

For Ted, his goal of 'taking care of others' is reliant on him being healthy and acts as motivation for him to control his diabetes. He needs to be healthy in order to fulfil his duty of care. For others, such as Brian below, this role comes about from the need to protect his loved ones from the possible dangers associated with him being

hypoglycaemic. In this case he takes steps to better his control in order to protect his wife from becoming physically hurt.

*Brian: Age 36 years, diagnosed at 2 years. (line: 791-805)*

thankfully I haven't had a really bad hypo for a long long time now but I think, em, just by, I'm worried that by accident I'll do something really bad like, sort of hit, hit my wife or something like that...[lines omitted]...I always tell her that if that happens then she should just call the bloody ambulance rather than doing anything herself but yeah, I worry that I'm sort of going to hit her, or sort of, thrash about and hit her with my elbow or kick her or something, push her downstairs or something like that, you know just anything along those lines, I just, it's it's a worry and it's another reason why I try and control it as well as I can because that would just be, I I can't, can't intonate how bad that would be em, and I think I have, I have kind of bruised her before when I've been thrashing about and she's tried to glucagon me and I feel terrible about that when that happens, I mean she says 'that's life'.

Brian's account is heavy with expressions of worry and concern for his wife's well-being. Brian must protect his wife from harm but his role is complicated by the fact that he is the possible perpetrator of such harm. He expresses his worry that he may hurt her while he is hypoglycaemic and unable to control his actions, and his terrible guilt at previous occasions in which he has bruised her.

His wife's duty of care to him puts her well-being at risk so Brian tries to protect her by instructing that she should get an ambulance rather than try to administer a glucagon injection to him by herself. He further protects her by trying to control his blood-glucose levels more tightly and thereby minimise these incidents. Whilst these steps may ease the situation, they do not relieve Brian of his worry that he may hurt his wife again, and the terrible guilt caused by hurting her in the past. Whilst Brian struggles with these concerns, his wife accepts them as part of life.

There is a reciprocity of care here between Brian and his wife. Ultimately, Brian



takes the steps to prioritize his wife's well-being and achieves this by tightening his blood-glucose control – a step which is consistent with healthcare recommendations. At the same time Brian's wife is accepting of the potential dangers of hypoglycaemic events, and her role in trying to bring such events under control. I liken Brian's role here to that of 'protector' which is synonymous with traditional masculinity. Here, this role promotes diabetes management and manifests itself in the presence of dependants. As such, this is a role which is often absent in the interviews with younger men and only comes about when they enter into long-term relationships or have children. These changes in personal circumstances act as 'turning points' and require men to re-engage with the process of adjustment. As a result, recognition of the seriousness of diabetes, and the potentially debilitating effects of the disease, develops. Along with this realisation can come a shift in personal goals and a new approach to diabetes management, as demonstrated by Darren:

*Darren: Age 22 years, diagnosed at 4 years. (line: 429-432)*

**I: But is that [erectile dysfunction] something that concerns you?**

D: Em yeah, I've always, when I was younger I always sort of said, nah that'll hit me when I'm my dad's age, I don't need to worry about that but em, now I'm sort of getting a job it feels like I'm growing up a bit and I need to start thinking about these sorts of things.

In the case of this extract from Darren (aged 22), the 'turning point' is finishing university and starting his career, a change which he sees as him 'growing up'. With this comes a new appreciation of the potential for diabetes-related complications, in this case Darren is concerned by erectile dysfunction which affects between 27 and 75% of men with diabetes (Bacon et al., 2002). Darren's new attention to his sexual functioning may be representative of a shift in goals, relative to changing life-stages, thus illustrating the evolving nature of adjustment to diabetes. Darren was not concerned by the issue of sexual-functioning when he was younger, but now as he contemplates his future, the potential for this complication has become relevant to him and will, perhaps, inform how he chooses to manage his disease.

#### ***4.1.3 Reassessing the relationship with diabetes in light of complications***

My use of the term 'relationship' follows Watts, O'Hara, Trigg (2010) consideration of the 'interaction between person and illness' (p. 493). Participants in this study were forced to assess how they interacted with diabetes in response to diabetes-related complications, be they physically present or a talked about possibility.

Here, I suggest that complications possess an evolving role in diabetic life, existing as a far-off possibility in the early days (as demonstrated by Darren in the last extract and Liam below) and being forced from this position of shadowy consciousness by the onset of 'warning-signs' - early indications of complications - later in life. These 'warning signs' frequently represent a turning-point for participants, causing them to stop, reassess their personal goals and determine if their current management of diabetes is going to continue to facilitate the pursuit of these goals. Quite often their mortality is highlighted by these 'warning signs' and a shift from short-term to long-term goal satisfaction is made. For others, the presence of complications represents a challenge to their moral identity as a diabetic.

Liam (27 years old) was diagnosed with Type 1 diabetes four months prior to participation in this study. The view of complications that he offers appears to be quite laid-back; they were not talked about seriously in hospital and he feels that they only happen to people who really do not look after themselves.

*Liam: Age 27 years, diagnosed at 27 years. (line:192-204)*

**I: Did the hospital talk to you about possible complications?**

L: Losing your legs? They threw them in. I'd say you'd have to really not look after yourself. That would be my guess.

**I: Do you feel like you're, that its not going to happen to you?**

L: Yes.

**I: Is that because you have a normal life or just because you haven't thought about it that much?**

L: I just don't see the point in worrying about it until something happens. If something like that did happen she'd have to push me around in a wheelchair.

**I: She'll love that.**

L: Once you are working, say if you're sitting at home or something you probably wouldn't keep it as well under control. But when you're working you keep it.

Here, physically working is an aid to good blood-glucose control and the absence of such activity may lead to poorer control and health complications. Thus, the suggestion here is that being a man (and working hard) aids diabetes management. Liam also places his partner within a traditionally feminine role of carer and suggests that her duty will be to take care of him should he lose a limb through complications in the future. By evoking these hegemonic images of gender roles, Liam is perhaps bolstering his masculine identity and also gaining a sense of assurance that should complications come about, he will have the support of his partner.

For many of the men in this study, it was not until complications moved from threat to reality, that this sense of assuredness was compromised. In the extract below, Brian discusses his reaction to being put on cholesterol-reducing drugs. This recommendation from his doctor acted as a 'wake-up call' for him.

*Brian: Age 36 years, diagnosed at 2 years. (line: 175-206)*

it's another of those things I guess that's a bit kind of, not going to happen to me, you know so you understand that there are these problems but you think, well I look after myself, I exercise, I keep fit, I eat sensibly, hopefully it won't, it won't affect me and I think...[lines omitted]...the first time I came up against any proper complications or suggested complications and it did kind of, eh at that point I tried, tried to stop eating rubbish and I said well you know I'll eat bran flakes for supper and wholemeal bread and all that, and I still do that, I still eat sensibly, don't eat too much rubbish although I have a tendency still to occasionally go for the odd ice-cream and whatever, em, but, but yeah it was kind of a wake-up call even though it wasn't a necessary wake-up call at the time apparently, em

**I: So is that motivation for you to try**

B: That is what made me get, eat more healthily cos obviously cholesterol is almost entirely through your diet em, so I always checked out the back of packets to see how much saturated fats were in 'em and whatever em, and yeah it was, it it was em, a sort of a motivational wake up call to say, be more sensible, you muppet ((laughs))

**I: ((laughs))**

B: em and eh so, so yeah, that that that was a big reason why I started improving my general regime and taking more care of myself, em, I think ((laughs))

Brian moves from talking about the shared understanding of people with diabetes (*you understand*) to focusing on his individual responsibility for preventing complications, and accountability for the onset of the complications to begin. He places himself to the centre of the problem and the resolution by recognising that he was eating poorly and thus adopting what he sees as more sensible food choices. In light of the threat of complications, Brian reassesses his meaning of diabetes and how it relates to his personal goals. Brian now affords diabetes more room in his life and takes the necessary actions that will allow him to achieve his newly-desired healthy lifestyle.

For Michael, on the other hand, we see a continued effort to minimise and reduce, not only the presence of diabetes, but also the significance of complications.

*Michael: Age 60 years, diagnosed at 6 years. (line: 866-876)*

I don't call this a major amputation, I call that a blip. All it was, that's the big toe, it must have chaffed somewhere, got a little blister, I shower everyday, but who looks underneath the feet? You know you're supposed to get the mirror but who does? Who does? And em, it was too late to save it. So, now I do use a mirror ((laughs))

**I: It sounds so simple**

M: Yeah yeah, I can cope with that, I can cope with losing other toes, I don't think I will cos I'm careful. Oh I had a blip, I missed

out there em and nobody told me this would happen. They told me it happens to bad diabetics but I'm a good diabetic or I was until that happened anyway. Em, I still think that I'm a good diabetic but em if they were to say 'you're going to lose both your legs', well I think that could well be the end of me. I don't think I could manage, I wouldn't want to manage.

'A blip', 'a little blister'; Michael actively minimises the significance of his complication. The personal accountability he concedes for 'missing' the blister is balanced by a seemingly shared failing of people with diabetes to follow foot-care guidelines ('you know you're supposed to get the mirror, but who does?'). His identification as a 'good diabetic' and his ability to cope with the current amputation may be symbolic of traditionally masculine mastery and strength; however these traits are in a fragile position and would undoubtedly be compromised should further amputations occur. Indeed, it would appear that while Michael may be able to cope with the amputation, he does struggle to make sense of why it happened to him, given that he sees himself as a 'good diabetic'. The contingency between one's moral identity as a diabetic and their diabetes-related health is illustrated as the onset of Michael's complication renders his identification as a 'good diabetic' vulnerable. By viewing himself as a 'good diabetic' Michael suggests that he felt immune to such complications adding that he was told they happen 'to bad diabetics'. 'They' one can assume refers to members of Michael's healthcare team, i.e. diabetic nurses and doctors. Thus it would appear that their judgements as to what makes a 'good' or 'bad' diabetic have been imposed on Michael. It may be the case that Michael strives to minimise the significance of the amputation, therefore, in an attempt to safeguard his position as a 'good diabetic' but by his own admission this is not easily achieved ('or I was until that happened').

For others, like Paul (below), reassessing the relationship with diabetes, and changing the way one manages their disease, is not only dependent on personal determination but on the collaboration and encouragement of healthcare professionals also:

Paul: Aged 45 yrs, diagnosed at 20 years (lines: 266-275)

P: He thinks he should just come in, look at your book and everything should be perfect. Just check everything. My blood sugars were running high, wasn't that good. He started losing his head. He turned round and said to me, 'you are just wasting my time'. Next time I'm back in again and I saw him again. Sat down at the table and the next thing his mobile phone rang. He chatted on the phone. This builder had rang about a price for this work. He was ages on the phone. Three different calls he had that time while I was in.

**I: I'd have lost the plot.**

P: He was nasty. That wasn't right, that wasn't right. I said, there is no way I'll go back there again.

At the time of the interview, Paul was forty-five years of age and had worked as a builder for in excess of thirty years. By his own admission, he had neglected his diabetes at times and had recently developed signs of retinopathy in one eye, which could potentially result in blindness. Appreciating the seriousness of this complication, and establishing as his goal the prevention of it worsening or further complications developing, Paul changed his relationship with diabetes. He enrolled in a DAFNE course, and started to keep a record of his blood-glucose readings (which he refers to in the extract as 'the book'). However his changing style of management did not result in immediately improved blood-glucose control, much to the anger of his consultant.

This extract illustrates the potential tensions of the health-care encounter when the balance of power is tipped in favour of the health-care professional. Paul is effectively positioned as a child who is being scolded by his 'teacher' because his 'homework' (the book) does not meet the standards demanded by the diabetes-regimen. The consultant's time is privileged and should not be wasted but no concern is given to Paul's time in his next visit, as he waits for his consultant to finish his personal calls. My interaction with Paul during this account changed from 'researcher' to 'fellow-diabetic'. As my reply would suggest, I was angered by his treatment. Paul's subordinate status in the healthcare encounter has discouraged him from attending meetings with this consultant; and in the rural part of Ireland where

he lives, alternative diabetes specialists are not available in his area. The danger here is that he will fall away from his clinic without the skills necessary to prolong his life and minimise complications.

Not all healthcare relationships are informed by the same power-differential as that of Pauls. Indeed an analysis of the way men in this study depicted their encounters with healthcare professionals illustrates the various ways these relationships may be constructed. Darren, below, uses a popular analogy in men's health literature to depict his particular experience:

*Darren: Age 22 years, diagnosed at 4 years. (line: 651-653)*

**I: Mm, what do you see their job as? What should they be doing for you?**

D: Em I suppose it's like mechanics. You go in for your service every ((laughs)) twenty thousand miles, or in for a check-up em, I guess that's the way it should be.

In Darren's case, the representation of the check-up as a 'routine service' is demonstrative of a healthcare relationship in which Darren has responsibility for the self-management of his diabetes while his healthcare team, perhaps, deal with routine checks that are beyond the remit of his role (for example, blood tests, retinopathy scans etc.). This is a relationship that Darren certainly appears to be happy with, and is in stark contrast to that depicted by Paul. The mechanical reference made by Darren is a common feature of men's health discourse, in which the depiction of men's bodies as machines is a common theme. This theme receives greater discussion in Chapter V as it is particularly relevant to men's discussions of their bodies in an online forum.

While Darren has established a system of collaborative care, in which he self-manages and his healthcare team occupy an auxiliary role, for others like Michael (below), the dynamics of the relationship between 'patient' and doctor may be less cooperative.

*Michael: Age 60 years, diagnosed at 6 years. (line: 311:313)*

Yeah, I control it to suit me and not what the specialists say. My, my consultant doesn't dictate the way I should run my life

This extract gives an insight into the encompassing nature of diabetes-management. Michael links controlling diabetes with how one lives their life, suggesting that the two are inter-linked. One cannot control or manage diabetes as a disease in isolation; rather it is informed and influenced by how one lives their life. Thus, healthcare professionals' recommendations of how diabetes should be managed are interpreted as directives of how Michael should run his life. Michael's rejection of such directives could be interpreted as his way of maintaining personal control over his diabetes and his life. It is important therefore, to recognise the potential 'power-battle' which may mark the healthcare encounter. Some may perceive the issuing of directives as authoritarian and reject such directives outright in an effort to protect personal control. Thus, special attention should be given to how healthcare recommendations are delivered in order to maintain a power-balance, in which the expertise of both patient and practitioner receive equal recognition.

## **4.2 Discussion**

Despite growing interest in the field of men's health, there is still relatively little known about men's experience of life with diabetes. As noted by Leonard (2004) above, men's accounts of diabetes-related issues have been largely neglected. This chapter, therefore, provides a relatively novel insight into men's experience of the disease. This study set out to gain an understanding of how men experience life with Type 1 diabetes. My analysis of participants' accounts of living with Type 1 diabetes suggested that men's relationship with diabetes is informed by their personally held goals. They control this relationship in a way that serves to facilitate the achievement of these goals. By reducing the seriousness of diabetes they are free to stray away from the recommendations of the care-regimen in favour of the pursuit of such goals. As personal goals change, in response to changing life-circumstances, one's relationship with diabetes also has the potential to change particularly when adherence to the care-regimen is viewed as the vehicle through which new goals shall be achieved.



It is important to acknowledge that this account of adjustment to life with Type 1 diabetes is borne out of a cross-sectional rather than a longitudinal design. While longitudinal qualitative research has been conducted in the field of diabetes research, (e.g. Lawton, Rankin, Peel and Douglas' (2009) study of transitions in diabetes care; and Casey, Murphy, Lawton, White and Dineen's (2011) examination of the factors impacting the assimilation of DAFNE into daily living), given the time-frame of this research, a longitudinal design was not feasible. In keeping with the epistemic position detailed in Chapter 3, I have treated participants' reflections on their experiences of living with diabetes as true to their knowledge, and thus the theory presented here is a representation of such truths.

The centrality of personally-held goals to the experience of life with diabetes has previously been highlighted by Watts et al. (2010). Their by-case analysis illustrates the potential for psychological conflict, as individuals are forced to contemplate the trade-off between personally-held goals and diabetes-related goals. The authors conclude that the satisfaction of both sets of goals (personal and health), need to be attended to if psychological and physical quality of life is to be achieved. Similarly, a focus on 'life goals' rather than the universal health-recommendations associated with diabetes were characteristics of what Paterson, Thorne, Crawford and Tarko (1999) referred to as the 'differentiated self'. The authors note that the 'differentiated self' is the result of a process of transformation in which the individual with diabetes learns to separate themselves from the disease whilst also feeling capable of controlling diabetes rather than being controlled by it.

Indeed, I would argue that the core category of the process of adjustment presented here is to exert *personal control* over diabetes in a way that facilitates the achievement of personal goals. Controlling diabetes in this case, does not equate with controlling blood-glucose levels or controlling diet. Rather it refers to men's attempts to control the presence of diabetes in their lives - by ignoring it to pursue personal goals such as work, or attending to it in order to achieve the goals of 'taking care of others'. Koch, Kralik, and Taylor, (2000) saw the experimentation with doctor's recommendations by men with diabetes as a means to maintain control and find a personalised 'fit' for diabetes in their lives. We have seen the same efforts to

personalise the care regime in this study as doctors recommendations were often taken into consideration but ultimately each participant pursued a system of 'best fit'. Broom and Whittaker (2004) noted the multiple meanings associated with control in their study on Type 2 diabetes. They noted that '[c]ontrol is simultaneously a biomedical statement about the management of blood sugar levels, a description of responsible compliance with medical regimes, an ability to manage other life stresses, and the triumph of the rational self over the disorder of the physical body' (p. 2380). They also found that 'control' has implications for the moral identity of someone with diabetes, as being 'out of control' in terms of blood-glucose levels results in the identification as a 'bad diabetic'. Indeed, a crisis of moral identity was observed here as 'Michael's identification as a 'good diabetic' was challenged by amputation.

In the initial stage of the adjustment process presented here, men reduce the seriousness of diabetes, demoting its definition from that of a serious illness to a mere 'nuisance'. This meaning has a very important function, that is, to guide how the management of diabetes will be incorporated into daily life. By reducing the seriousness of diabetes men lay the foundation for a life within which diabetes will cause minimal intrusion. In this way, men can allow themselves the freedom to move away from the recommended diabetes regimen and enjoy a lifestyle that is informed by personal choices rather than enforced routine. In a similar way, Peyrot, McMurray, and Hedges' (1988) study with diabetic men refer to a coping strategy, which they called 'normalization', as an attempt to minimise the intrusiveness of diabetes in their lives. While Charmaz (1994) proposes that men attempt to control definitions of illness and disability in order to preserve self and maintain control over their own lives. Indeed, such preservation of self could be identified in men's attempts to 'power-through' and ignore their diabetes while engaging in physical labour.

Work was very relevant to the men in this study and has also been noted as key theme in diabetic men's accounts elsewhere. For example, Broom et al. (2010) found that diabetic men raised the issue of work in their accounts more often than diabetic women, and particularly pointed to the difficulties in complying with the diabetes-regimen while at work. Here, engaging in work acted as one of the main inhibitors to

adherence to the recommended diabetes care-regime. Within the workplace, the bar of achievement and ability is consistently set by non-diabetic male colleagues and the desire to be identified as a 'normal' man may compel those with diabetes to push it to the boundaries of medical recommendations and strive to reach an equal status of masculinity. Similar observations have been made by other researchers in the general men's health literature who noted that men's health behaviours serve to situate them within the masculine arena (Courtenay, 2000) and that men who endorse traditional masculinity are less likely to engage in health-promoting behaviours and have greater health risks than men who do not (Mahalik, Burns, & Syzdek, 2007). However, some diabetic participants in Hjelm, Bard, Nyberg, & Apleqvist (2005) study reported that being employed was good for their health, as frustration caused by unemployment increased their stress levels which in turn caused their blood-glucose level to rise. However, their sentiments related more to the effect of *unemployment* rather than the consequences of full employment to their diabetes care-regime.

The workplace here also acted as the arena in which disclosure of diabetes occurs, either intentionally or unintentionally. Many of our participants admitted to reluctantly disclosing their diabetes to a colleague so that he/she would be able to treat an attack of hypoglycaemia effectively. For others, such as Anthony (above), disclosure came after such an attack, which served to undermine his attempts to exhibit a 'normal' male persona. What follows after such disclosure is what Goffman (1963) referred to as 'covering', in which Anthony makes 'a great effort to keep the stigma from looming large' (p.102) by avoiding conversations about his diabetes. Other researchers have demonstrated that this reluctance to disclose illness in the workplace is more common in men than in women (Munir et al., 2006).

Ultimately, the workplace represents the arena where men may demand of themselves an expression of masculinity through ability and strength equal to or better than that of their colleagues. Our research would suggest that this orientation is prominent with our sample of diabetic men; chronic illness does nothing to quieten this desire. Many of our participants sought to reaffirm their definition of masculinity through work, striving to maintain control over diabetes by prioritising work tasks and identities. However, outside of work, this emphasis on the expression

of male identity was not as important.

The goal of 'taking care of others' in which men felt responsible for the welfare of others, served to promote increased attention to diabetes and the diabetes regime. This particular ideal was most common in participants who were over thirty years of age and at the stage of life where they were entering into serious relationships or having children. These circumstances brought a shift in focus from their individual experience of diabetes to that of the wider potential of the disease. It is at this point that they reassess the meaning they have attributed to diabetes (i.e. as a serious disease or a 'nuisance') and subsequently choose to pursue actions which compliment this meaning. For example, a younger man saw diabetes as an interference during his teenage years and chose to ignore it in order to socialize with his friends, may later appreciate the serious implications poor attention to his diabetes can have on his life-span and his ability to take care of his children, thus bringing about a change in the way he manages his condition.

Gender was made relevant in men's accounts in a number of ways. Firstly, the overarching theme of establishing personal control over diabetes, as opposed to complying with healthcare recommendations, could be viewed as an attempt to preserve autonomy over one's life. Alongside an emphasis on 'working hard' and references to ability (mastery), references to traditional masculinity were present in men's accounts. However, masculinity as a concept was not steadfast. For James, for example, the performance of hegemonic masculinity was context-specific: performed in the presence of other men in order to save face. For Ted, its performance was recognised as being 'old-fashioned' and situated as something in the past; he no longer pursues such performances as he now knows better. The prevalence of the goal 'taking care of others' demonstrated that men's accounts were not in anyway dominated by references to traditional masculinity, nor were their health-related behaviours governed by principals of hegemony. Thus, as Speer (2001) stated, 'masculinity is not a mapping notion' (p. 126) as the performances and uses of masculinity here, varied both between participants and *within* participants over time.

The onset or threat of complications promoted greater attention to diabetes in many

men. Through this analysis, we can appreciate the evolving presence of complications in one's life, moving from a hypothetical threat to a worrying reality. As complications become increasingly relevant to one's experience of diabetes, their account of the seriousness of diabetes may change; bringing with it a reassessment of their relationship with the disease. For some, however, a continued effort to reduce the seriousness of the disease was made despite worsening health. For others, difficulties were encountered as they attempted to establish a new relationship with diabetes, with a view to improving health. As demonstrated in the case of 'Paul', little recognition was given to his personal situation. Rather he was disciplined for not fitting in with the general healthcare recommendations regarding blood-glucose levels. Hornsten, Lundman, Selstam and Sandstrom (2004) warn that such 'dissatisfying' clinical encounters may threaten the perception of self and identity of patients with diabetes.

Life-stage appeared to play a role in how men chose to live with diabetes, with a reassessment of one's definition of diabetes following the birth of a child or the progression of a relationship. Backett and Davidson (1995) also noted a change in health practices in men entering these stages of life, while Robertson (2007) argues that hegemonic ideals change in response to these evolving life-stages with the ideals of younger men varying to those of men who are entering relationships and fatherhood. Lawton (2002) suggests, however, that such changes in health-related behaviour across the lifecourse tend to be *reactive* to worsening health as opposed to typical of a specific life-stage. This is also consistent with the findings here as a change in diabetes-management came about in response to the onset or threat of complications. It is important that such changes in management are supported and encouraged by health-care professionals.

In the absence of similar analyses of interviews with diabetic women, it is impossible to suggest that the process of adjustment to Type 1 diabetes presented here is unique to men with diabetes. However, the literature would suggest a notable difference in adjustment to life with diabetes between men and women, where men attempt to reduce the significance of illness by separating personal and 'ill' selves, while women incorporate illness into their personal identity. This has been demonstrated by Helgeson & Novak (2007) in their study with adolescents with

diabetes found that females viewed diabetes as more central to their self-concepts than males. Similarly Williams (2000) found that adolescent boys made every effort to keep diabetes and asthma outside their identities by 'passing' (by not injecting in public and by not talking to their friends about diabetes) when compared with girls who incorporated the conditions and regimens into their personal and social identities.

### **4.3 Summary**

This chapter offers a theory of adjustment to life with Type 1 diabetes based on the experience of 15 men with the disease. The ultimate goal of adjustment is to achieve personal goals by controlling the influence of diabetes on one's life. The ever-evolving relationship between diabetic and diabetes is highlighted as personal goals shift in response to changing life events and personal circumstances. The reassessment of one's relationship with diabetes is necessitated in response to these changes, which in turn informs how men manage their diabetes. I also noted that the extent to which gender influences health-related behaviours varied between men in the study. The fluid and malleable nature of adjustment reflects the chronicity of the disease and, in light of this, it is recommended that healthcare intervention should take this potential to change into account when prescribing regimes. The viability of prescribed regimes should be routinely assessed to ensure that they allow for both 'normal' and healthy living. I suggest that it is only through the carefully considered collaboration of patient and doctor will personal goals and long-term health be achieved.

**Ch. V: How men and women respond to the prospect of a sexless relationship:  
A grounded theory analysis of postings taken from an online diabetes forum.**

**5.0 Introduction**

By transcending mobility boundaries, the internet is actively becoming a significant part of the lives of people with chronic illness and providing them with instant access to medical information and patient stories. Alongside the instant provision of health-related information, internet support groups (in a variety of forms such as chat rooms and discussion boards), allow those with chronic illness (and any other groups of people with similar interests) to partake in a virtual community where personal experiences of illness can be shared, support given and received, and medical information exchanged.

The health contexts within which online support groups receive most popularity are those Davison, Pennebaker and Dickerson (2000) refer to as the stigmatizing diseases (such as AIDS, alcoholism, breast and prostate cancer). In these cases, online forums for these groups acts as a source of support as their stigma sets 'them apart from their immediate social setting and propel them toward others who have been similarly marked' (p. 10). The psychological benefits of participation in these groups have been documented. Rodgers and Cen (2005) found that the longer women with breast cancer belonged to, and participated in, an online community the more positive their attitudes towards breast cancer became. While Barak, Boniel-Nissim and Suler (2008) found that participation in online forums foster: 'well-being, a sense of control, self-confidence, feelings of more independence, social interactions, and improved feelings', which overall, they refer to as 'empowerment' (p. 1867).

With regards to online forum use by people with diabetes, Zriebiec and Jacobson (2001), found that people with diabetes used an internet support group to obtain emotional support and to exchange information with other users. These benefits of membership of an online forum can also be likened to those identified by Greene, Choudry, Kilabuk and Shrank (2010) in their analysis of Facebook groups dedicated

to discussions on diabetes. Their study found that members of these Facebook groups gain 'interpersonal and community support from wallposts and discussion threads, they access forms of specialized knowledge on diabetes management from peers, and can articulate positive but realistic self-images as diabetic individuals and a mobilized diabetic community' (p. 291). Ravert, Hancock and Ingersoll (2004), echoed these findings in their study, concluding that adolescents with Type 1 diabetes use these online forums for support, information, advice and shared experience. The authors also noted a gender difference with regards to forum use: females used the forums more often than males, while males were more likely to use the forum to obtain information about diabetes, than were females. The accuracy of information exchanged in these online forums was assessed by Hoffman-Goetz, Donelle and Thomson (2009). In their study, the results of a content analysis of online conversations amongst retired people with Type 2 diabetes, were compared with clinical practice recommendations. The findings indicated, when judged against medical recommendations, the information exchanged by forum-users was accurate. Case et al. (2009) used an internet-based diabetes self-management programme to examine differences in forum-usage by different racial groups and found little variation between these groups in their online-usage. While the authors used an internet-based diabetes forum to conduct their research, their focus was on the interaction between race and internet-usage and as such, diabetes did not inform their research or results in any way. Nonetheless, their results are important in promoting the use of online-forums as beneficial to all users, regardless of race.

As mentioned, Ravert et al. (2004) noted, in their study of online-forum use by people with diabetes, that more women used the forum than men. This difference has also been observed amongst other illness groups. For example, Lieberman (2008) identified that almost twice as many women as men used online cancer support-forums. A possible cause for this gender difference is, according to Lieberman (2008), 'men's tendency to avoid disclosing personal information that might make them appear weak or vulnerable' (p. 167). This causation is underpinned by traditional assumptions of masculinity, and has also been noted by Seymour-Smith (2008) who found that men who attend testicular cancer self-help groups 'work hard to construct their self-help group, and hence their own identity, in a way that conforms to the dominant characteristics of strength and not weakness' (p. 795).



Gender differences have also been observed in the way men and women use these forums. For example, Ravert et al. (2004) noted that men with diabetes used the online forum to obtain information regarding their disease more often than women. Zakowski et al. (2003) found greater emotional expression in women with cancer than men with cancer. Sullivan (2003) also explored the area of gendered cybersupport in ovarian cancer and prostate cancer forums. The author noted that women used the forum as an opportunity to 'vent' feelings and obtain emotional support. They noted that men, on the other hand, communicated to one another in highly technical language and it was rare to find postings with dominantly emotive content. While Gooden et al. (2007) did not observe a considerable difference in the frequency of emotional expression in men and women (forty percent of women's communication incorporated emotional content compared with thirty-four percent in men's), the authors did note a difference in the way emotions were expressed with women expressing emotions open and clearly whilst men tended to imply their emotions. Indeed, Lieberman (2008) found that men with Parkinson's disease, who used online support groups, expressed significantly more negative emotions (anger, sadness and anxiety) than men with cancer. It may be the case, that the way men use online-support forums varies in response to their specific health situation. Men who suffer from a potentially life-threatening, but also potentially curable disease, such as cancer, may be more focused on obtaining information relevant to their treatment and prognosis, while the supportive properties of the forum may be more relevant to men with chronic diseases, such as Parkinson's disease.

From a research perspective, the postings to online forums serve as a valuable source of naturalistic data. They are free from any potential influence of the researcher and thus, postings represent the sentiment of the forum-user as opposed to a deliberated response to a question posed by an interviewer. They also allow me to access discussions of topics men may feel uncomfortable talking about in a face-to-face environment, such as an interview-setting. Additionally, forum postings serve as a convenient form of data to the researcher. They are readily available on the internet and do not require a recruitment-drive. Finally, postings are in text-format, and thus do not require transcription. There are some challenges however, in using the online forum as a research tool. For example, the cultural diversity of the online

communities has implications regarding the generalizability of research findings (Gallagher & Savage, 2013), and the restriction of the researcher's role to that of observer means that it is not possible to probe or initiate additional discussion of a topic that may be particularly interesting to the research.

While research has explored the usage of online forums by people with diabetes (e.g. Zriebiec et al., 2001; and Ravert et al., 2004), I have not been able to locate a single study which has exclusively explored the usage of such forums by men with diabetes. In this chapter then, I consider the issues raised by men with diabetes in an online-support forum specifically dedicated to men with the disease.

## **5.1 Analysis**

Overall, the analysis provides an understanding of how heterosexual couples account for life with erectile dysfunction. The analysis presents themes relating to: the notion of man and body as separated, resulting in the externalisation of sexual-functioning from the body and the contested causation of ED, men and women's accounts of the importance of sex, and, finally, men's reported emotional reaction to feeling unable to satisfy their partner's sexual needs. Throughout, gendered lines are blurred with the suggestion that individual elements, as opposed to gender norms, inform the experience of life with ED. Three categories were generated from analysis of the data; *The separation of man, body, and responsibility* with the sub-category of *contesting causation*; *Does sex really matter?*; and *Expressing emotion*. The core category was determined to be 'Sharing ED', a process which highlights the centrality of the couple to the experience of ED.

### ***5.1.1 The separation of man, body and responsibility***

Analysis of the postings suggested that there is a separation of man and body in the case of diabetic men affected by erectile dysfunction (ED). This separation is manifested in the accounts men offer regarding the causation of ED, the way men use nicknames when talking about their penis and also in the way they present a disconnection between sexual desire and the ability to engage in sex. The following extracts from 'Henry', which appear in separate threads on the forum, illustrate the

various ways separation is manifested.

**'Henry'<sup>2</sup>**

A few years back, my body devolped ED as well. Its "root cause" was from too much over weight, was from lack of being "fit" (as in health fit - not visual looking fit), it was from "too much" weekly routine and it was from the cold / depressing winter weather

Henry confines the diagnosis of ED to his body, something which is separate to himself, but also suggests personal agency in the causation of ED, through physical phenonemena (weight and fitness). However, by citing the factors of 'weekly routine' and 'cold/depressing weather', Henry is also able to place the blame on external factors, thereby limiting his personal responsibility for the presence of ED. Henry further demonstrates the temporary separation of man and body in the following extract which has received 12 replies and has been viewed 2,020 times:

**'Henry' *Didn't realise it was the important....***

[lines omitted]

For years, my ED has gone "down hill". With T2 and older age, my ED is going down hill even faster. Many times I would often say to my wife "not today honey - I want to but the equipment isn't ready today". And not doing it didn't bug me at all. Like some men, I'm at the age of "been there, done that, no need to do it anymore" things. Just last week, the equipment decided to work. Probably because my BG numbers and my extra body weight is coming down.

[lines omitted]

Here, the cause of ED is attributed to Type 2 diabetes ('T2') and natural ageing. As a result Henry is forced, on occasions, to reject his wife's sexual advances despite his personal desires, as his body, or 'equipment', is unable to engage in such advances. On other occasions however, Henry tells us that the body 'decides' to work, offering

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<sup>2</sup> Data are reproduced as they appeared in the online posting inclusive of grammatical errors.

an understanding of the penis as an independent entity capable of functioning on its own terms. The use of the word 'equipment' conveys an understanding of the body in mechanical terms, similar to that noted in previous men's health research (e.g. Gough, 2007; Gough & Conner, 2006). Henry attributes his ability to engage in sexual intercourse as a result of his weight loss and improved blood-glucose (BG) control – an indication that despite the separation of man and body, Henry can exert some control through will-power and a desire to lose weight. In addition to the separation of man and body, Henry also separates himself from any potential personal loss by minimising the impact of ED on his life. It 'didn't bug' him and this is because sex has already been a part of his life. The reference to 'been there, done that' may serve to protect his masculinity in the face of sexual inability. The suggestion is that sex was a part of his life previously to the extent that the present absence of it is not too concerning. If masculinity is to be measured in terms of virility then Henry has already proven his worth in his younger days. This acceptance of ED can be likened to the dominant social constructions regarding older sexualities which Oliffe (2005) highlighted. Participants in his study avoided 'emulating a caricature or parody of a younger man's "natural" masculinity' (p.2255) by accepting sexual dysfunction as a result of age and treatment of prostate cancer.

The separation of man and body is also demonstrated in a reliance on external intervention in an attempt to restore functioning. Medical intervention may also assist in the fulfilment of sexual desire, as the following extract from a man with Type 2 diabetes suggests:

**'Dan'**

Nothing was working very well down there so I had to take the next step, I am now injecting Trimix into Mr, Limpy and he has turned into Mr. Hot Rod. I am more than willing to share details on the thread or, if you prefer, feel free to send me a PM.

This particular posting has not received any replies but has been viewed 474 times. However, it may be the case that 'Dan' has received responses via private message (PM). As in the previous post where Henry uses the word 'equipment' to refer to the penis, here 'Mr. Limpy' and 'Mr. Hot Rod' both replace the word penis whilst also

indicating its sexual in/ability and how this ability is enhanced by medical intervention. Rather than expressing sexual ability in personal terms, it is confined to 'down there' suggesting that it is separate from the individual. Alternatively the use of the term 'down there' along with the frequent use of nicknames for the penis throughout the postings, may serve to ease any potential embarrassment caused by discussing this issue. The progression to medical intervention is described by Dan as a necessary 'next step' because 'nothing was working', suggesting that a schedule of intervention exists in the treatment of ED. The success of such intervention (and resulting transformation) is experienced by his penis rather than by him personally. Viewing the penis as separate and independent in this way is consistent with what Potts (2001) referred to as the 'penis-self' which is 'granted interiority; that is, consciousness, a mind (will) of its own' (p. 151).

The suggestion is therefore, that the diabetic penis is unresponsive to personal desires but responsive to physical change and medical intervention. Unlike 'normal' men, for men with ED there is a fragmented relationship between sexual desire and engagement in sex, and this can only be bridged by optimum physical health, advanced medical treatment, and as the following extract suggests, the timely and mutual desire of one's partner:

**'Jack'**

I agree that it's disheartening to swallow a \$12 pill only to later find the wife has a headache!!

This extract demonstrates the loss of control men with ED have over their ability to engage in sex. Here a '\$12 pill' provides the chemical assistance to engagement in sex but this is spurned by a lack of physical connection required as 'the wife has a headache', a term which is commonly understood as indicating a lack of interest in sex. By implicating his wife in this scenario, Jack further separates himself from the inability (and culpability) to engage in sex. Here we can see two discordant relationships affecting the potential for sexual intercourse; firstly between Jack and his ability to perform sexually (which is bridged by the \$12 pill) and secondly between Jack's sexual desire (and chemically-enhanced ability) and his wife's sexual desire, which has been negated by 'a headache'.

### *Contesting Causation*

Whilst men on the forum frequently separate themselves from the causation of ED, this is often contested by their partners accounts which offer an alternative insight to the diagnosis. As the following extracts suggest, women consistently position their partners as central to the cause of ED. As a result, these women strive to establish an interventionist role with regards to the management of their partner's diabetes, in the hope that it will result in improved sexual functioning and a decreased strain on marital life. The following postings have been taken from a thread started by 'Trish' and entitled 'New & Frustrated in Sunny So. Calif'. This thread has been viewed 1,610 times and has received 13 replies, some of which are shown below.

#### **Trish**

[lines ommitted]

Now 'John' (my husband) does eat whatever he wants, including donuts, cookies, etc. but like I said he says his numbers are low 100's. He does smoke, but has taken some meds to quite this in the next week or so. He is 52 and I am 45.....and getting EXTREMELY frustrated!!! Can anyone give me some advise, I really am not understanding what is happening and it is affecting our marriage.

[lines ommitted]

#### **Trish**

I neglected to add that we have tried Lavitra and Viagra, not helping.

This extract illustrates the peripheral role 'Trish' has in relation to the management of her husband's diabetes. Here she makes reference to his unconstrained diet choices which are fuelled by personal preference and vindicated by a vague testimony of healthy blood-glucose levels ('low 100's). While acknowledging his efforts to better his health by taking steps to quit smoking, 'Trish' situates her husband as central to the problem ('eats whatever he wants', 'he says his numbers are low') – a problem

which she does not actually explain however her subsequent reference to Viagra, which indicates that a sexual dysfunction is the issue. This problem is not only experienced by her husband, it has also left her feeling 'extremely frustrated' and is affecting their marriage. This account is consistent with research from Congalen and Congalen (2008) which highlighted the significant adverse effects of ED on the female partner's sexual experience. Here, the transition from the personal experience of diabetic life to the shared experience of sexual dysfunction is further suggested when 'Trish' says '*we* have tried Lavitra and Viagra'. The following response to Trish's post also situates her husband as central to the causation of ED:

**Sophie**

I would say, his numbers are not good as he says they are, or else  
you would not be having problems in the intimacy department  
[lines omitted]

This response also connects 'Trish's' husband to the cause of sexual dysfunction and builds on an air of distrust regarding his accounts of his blood-glucose levels. This distrust is developed further as Trish then shares details of attempts to access his blood test results and her determination to find out what is really 'going on'.

**Trish**

I tried accessing his blood tests so I could see his A1c number, but  
was unsuccessful for the moment. but I will...lol  
[lines omitted]

I have just started to get into this Diabetes thing, as I thought it was  
never really a problem before and he had it all handled, well now it  
is really affecting our marriage, this is why I want to know whats  
going on and NOT just taking HIS WORD ANYMORE.

Trish is building up her role in her husband's diabetes-care, moving from a position of naïve acceptor to educated intervener. This transition has been necessitated by the realisation that, despite her previous assumption, her husband does not have 'it all handled', and this has resulted in implications for their marriage. The marital stress caused by erectile dysfunction is shared by 'Kim' in her response below.

### **Kim**

[lines omitted]

My husband is not a diabetic, but from his own doing (cigarettes & alcohol), and genetics (high blood pressure), he suffers from impotence. This has been a HUGE stressor on our marriage. It's been four years of pulling teeth to get him to seek help.

[lines omitted]

This response challenges men's accounts of the body and causation of erectile dysfunction as being separate from the self. Here it is explicitly stated that erectile dysfunction is 'his own doing', resulting from a combination of genetic factors and poor lifestyle choices. The stress to their marriage, as a result of ED, is perpetuated by 'Kim's' struggle to get her husband to seek help. 'Ruth' offers an account of how she intervened in her husband's diabetes-care by removing the opportunity to make poor diet choices.

### **Ruth**

[lines omitted]

The first thing I did was dig out and trash my husband's candy reserve. Now when I go to the grocery, I shop with his needs utmost. I only buy what I know would be good for him to eat. Cookies don't live here anymore. If the food that is nothing but bad is not there he cannot eat it.

In order to take on responsibility for her husband's diabetes-care, 'Ruth' prioritises his needs. She abolished his personal reserve of sugary foods and now controls the food that comes into the home in a way that ensures his health-requirements are met. Her assumed responsibility for controlling her husband's food can be likened to the traditional role of women in the food provision for partners who were affected by prostate cancer in Mróz et al.'s (2011) study. Here, there is a suggestion that will-power alone will not suffice in improving her husband's diet, the only option is to ensure that the junk-food option is not available. Ruth's intervention could be likened to that of a mother. She has positioned her husband as a child, incapable of making



correct choices or exercising will-power.

Based on these, and many other similar postings on the forum, the separation of man and body (in the context of ED causation) does not exist from a woman's perspective. Instead blame is repeatedly attached to their partners' unhealthy diet and lifestyle choices. From the women's perspective, these men *choose* to neglect their diabetic health by subscribing to an unconstrained diet. It is their poor choices which leads to the onset of ED and the subsequent strain on marital life. As we will see in later extracts from 'Ian' and 'Ben', while men on the forum may contest the causation of ED, they do acknowledge the strain ED places on their marriages. The determined interventionist approach assumed by the majority of women here, can be understood as an attempt to reform their partner's choices (or to remove the poor choice option), with the intended effect of improving, not just their husband's ability to 'function' sexually, but their mutual enjoyment of sex and marital life. This interventionist approach is contrasted against the image 'Scott' offers in the following extract, in which the emphasis is on emotional support as opposed to practical intervention.

### **Scott**

[lines omitted]

Honestly I'm going through the same issue. My wife talks to me about. She don't threatening to go get a lawyer or cheat on me. She sits with me and we talk. Go for romantic walks.

Of course it's my anti-depressant. Thats causing my problem.

[lines omitted]

The 'issue' which Scott refers to here is the onset of ED. He presents ED as something which affects him, ('I'm going through the same issue', 'my problem'), and positions his wife on the periphery, as an emotional support who is available to talk to him in a non-threatening way. In the absence of sex, the intimacy in their marriage is maintained by going for 'romantic walks'. As with the previous extracts from men with ED, 'Scott' externalises the cause of ED to his anti-depressants. He presents this information in a matter-of-fact way, without any suggestion that other factors may have contributed. This is clearly distinctive to the postings from women regarding

the cause of ED.

### ***5.1.2 Does sex really matter?***

Postings on the forum often demonstrate dominant gendered views of sex (e.g. men associated with an innate sexual drive and women with a preference for romance and sensitivity) whilst others deviate from these and highlight the commonalities and contradictions that exist both between and within men and women's accounts of the importance of sex.

#### **Jack '*Here we go again*'**

[lines omitted]

I understand the deep biological need that we fellas have to keep everything "working"

[lines omitted]

Many postings on the forum refer to men's 'deep' and 'primitive' need to engage in sex; this particular posting however places the emphasis on the *ability* to engage in sex rather than the act of sex itself. The mechanical reference to keeping 'everything "working"' is linked with a 'deep biological need', something which according to Jack, it would seem, men are predisposed to. The suggestion here is that men should be primed for sex in order to fulfil their natural role. This role is developed further in the following extract from Henry. Here we can see that men's role is not only to be primed and capable of sexual function, but should also be mindful of their responsibility to satisfy their partners through the provision of sex. An analysis of the first five lines of this extract has been presented in the previous section.

#### **Henry (extract 2) *Didn't realise it was so important***

[lines omitted]

For years, my ED has gone "down hill". With T2 and older age, my ED is going down hill even faster. Many times I would often say to my wife "not today honey - I want to but the equipment isn't ready today". And not doing it didn't bug me at all. Like some men, I'm at the age of "been there, done that, no need to do it anymore" things.

Just last week, the equipment decided to work. Probably because my BG numbers and my extra body weight is coming down.

One romantic morning and afterwards, we snuggled up - under our warm morning blankets. Since then, my wife has been such a sweet lady. Walking around with smiles, bubbly, etc. etc. attitude. Didn't realize that certain actions (sort of speaking) are so important to my wife. It certainly perked her up...

Guys: If you have ED, do make the effort to "have fun" with your spouse once in the while. Do take the time to satisfy her as well.

And if possible, do get your ED fixed as well. Didn't realize "having fun" (sort of speaking) was so important to my wife...

[lines omitted]

Henry's posting has resulted from a recognition that sex is important to his wife. This, it would appear, is something which he never realised before as he titles his message 'Didn't realise it was the important...', and closes his initial posting with a similar statement. His wife is depicted as the instigator of sex, but Henry has the power to reject her advances or, when his body allows it, to 'satisfy' her and such satisfaction leads to a notably happier wife. Again, we are presented with a reference to the mechanical nature of male sexual functioning as Henry encourages other men to get their ED 'fixed' in order to provide their partners with sexual gratification. The suggestion here, from Henry's point of view, is that penetrative sex is important to women and is required if sexual satisfaction is to be provided. This evokes a varied response from women on the forum; some commend Henry for his attention to his wife's sexual needs, whilst many others (like Carol below), strive to minimise the importance of sex to women.

### **Carol**

Ok I've been thinking about this... and I think it's important to add, for all those men reading this, that a man with ED is NOT a failure, that we women don't need sex to know that you love us, and that you're no less of a man if you're having troubles with Mr Willy. Will you men believe that? Probably not, because it's deep inside you... it's primitive stuff! But let me tell you something... women

need hugs, they need words, they need foreplay, they need your attention, and they need to know you love them with actions as much as with words. That's more important to most women than sex or your income, even though men generally think those two things comes first!

The response from Carol to Henry's posting, is to contain the significance of sex and emphasise alternative ways of satisfying women, with the ultimate goal of making the woman feel loved. The proposal is that cuddles, touches, being made to feel special, hugs, words etc. are more important to women than sex. This challenges Henry's statement and suggests a distinction between how men and women think about sex: with men (or Henry at least) realising that it is very important to their wives while some women see it as less so. Carol suggests that men's view of sex is 'primitive' and resistant to change, therefore women's accounts of what is important are likely to fall upon deaf ears. Indeed the following posting from 'Matt' which appears on a separate thread entitled 'Anyone having ED problems???' would suggest that Carol is justified in thinking that men are dismissive of women's assertions that sex is not important. This thread has been viewed 9,568 times and has 40 postings.

**Matt (*anyone having ED problems*)**

Finally somewhere where I can discuss such a personal problem. I have had ED for about one year now. I have T2 for about 3 years now. I have the desire to but not the functioning to and it's frustrating. My wife says she's just as content without us having sex, but sometimes I feel like she's just saying that to make me feel better. I want to make her happy in the bedroom but cant achieve an erection long enough to.

[lines ommitted]

For 'Matt' the forum represents a haven where his 'personal problem' can be aired. His opening sentence would suggest that he has struggled to find a place to discuss this 'problem' until he found this forum. His problem is caused by the fragmented

relationship between his sexual desire and his engagement in sex, as he explains he does not have the (mechanical) 'functioning' to fulfill his desires. Whilst referring to this as a 'personal problem' he is clearly mindful of his wife's experience of a sexless relationship. Her assertion of contentment is viewed as an attempt to make him feel better as he links her happiness 'in the bedroom' with penetrative sex, something which he is unable to provide. 'Stephen' posts the response below to 'Matt's' message, which serves to link ED not only to diabetes but also to age, and at the same time promotes other forms of intimacy:

**Stephen**

[lines omitted]

Sorry to be negative but you may never return to the raving sex life you enjoyed before the problem occurred. You are not unique for our age group, some might say even normal

[lines omitted]

However, I would like to say it is possible to have an intimate loving relationship without regular sex, or at least only occasionally. Communication is the key. Everyone wants intimacy, and I don't mean sex here. Never stop talking, about anything, (the shopping, what happened at work, etc) and enjoy a laugh. Have lots of touching and cuddles and feel grateful that you have someone to share with.

'Stephen' positions himself as advisor or counsellor, someone who can identify with the problem, has truths to share and wisdom to offer. Here, and in other postings on this forum, we see references to a 'raving sex life' which existed prior to the onset of ED. Gullette (1998) refers to this as 'sexual nostalgia' (as cited in Potts, et al. 2006) in which youthful sex is held as a reference point against which one's current sex-life is compared. Stephen's account is consistent with what Gullette (1998) termed as the 'progress narrative'. Changes in male sexuality are acknowledged as normal for a certain age-group and to compliment such changes new sexual experiences (which are not reliant on penetrative sex) are pursued. In ways similar to 'Carol' earlier, Stephen presents various means to achieve intimacy. As Carol talked about love and sex, here Stephen distinguishes between intimacy and sex, and is of the opinion that

the former is universally desirable. As before, cuddles, touching and communication are emphasised as is an appreciation of having someone to share these things with.

Thus far we have noted a division in the importance men attach to sex. Sex is associated with heteronormative penetrative sex and is presented by some as the biological drive towards the gratification of men and women's sexual needs. This account of sex frames the erection as what Potts (2000) refers to as 'the essence of male sexuality' (p.85). On the other hand, some men appear to be more accepting of a loss of sexual-functioning. Their accounts suggest that intimacy and pleasure can be achieved without penetration. In many cases these men link ED with age and their previous experiences of a 'normal' youthful sex-life enable them to accept ED. This divide in the importance men attach to sex is mirrored in women's accounts. As demonstrated in the posting from 'Carol' (above) many women on the forum are keen to play down the importance of penetrative sex and suggest other ways to achieve intimacy. Others, like 'Melissa' (below), are aligned to the dominant notion of sex as penetrative and necessary if 'needs' are to be satisfied.

### **Melissa**

I really dislike generalizations about anything. I am the type of woman for whom sex DOES matter. I have no interest in a close roommate type of marriage. Many women supposedly say they are okay with infrequent sex. Perhaps they are or perhaps many are socialized to say just that.

According to the opinion offered by Melissa, it may be the case that women who offer alternatives to sex, are merely trying to ease the brunt of ED for the men who use this site (i.e. to protect them from feeling like 'failures'). Indeed, in the previous section, responses to 'Trish' would suggest that sex is important to women. The frustration borne out of a sexless relationship led these women to seek advice through the forum and speak with other people in similar situations. Feelings of frustration, stress and strain were consistently expressed (and often emphasised with the use of capitalisation) and such feelings led these women to adopt an interventionist approach towards their partner's diabetic care. The positioning of these women as being interested in sex for their own personal gratification goes

against the traditional view of sex which Hollway (1984) terms the 'male sexual drive'. Rather than acting as objects of men's drive these women refer to their own sexual 'needs' and the frustration which results when such needs are not satisfied.

Women's varied opinions regarding sex are also depicted in discussions of staying in a relationship affected by ED. The following discussion posted on a thread entitled 'Want to be Supportive' by 'Ann' address the appropriateness of staying with a partner who is affected by ED. This thread has been viewed 1,838 times and has received 5 replies.

**Ann**

I met a guy recently and we've dated a few weeks now. He is an incredibly sweet man and I'm growing very fond of him. Last night for the first time, things took on a more 'romantic' turn. He confessed he has type 2 and has ED. I could tell he was scared to tell me that, but I'm not a shallow woman. I would never make that a qualifier in deciding if I would become serious with someone  
[lines ommitted]

**Jen**

A woman is not shallow for walking away from a guy she is dating after finding out he has ED.

**Tina**

I'm sorry but a woman who walks away from a man because he has ED is very shallow! There are several ways to please a woman and vice versa!

**Linda**

If he has ED that is your decision whether you want to stay.  
If he does not take care of his diabetes, you may want to think about what a future with him may entail, too.

In the extract from 'Ann', shame and secrecy are alluded to as details of diabetes and

ED are released as a 'confession'. Despite her new partner's fear over such a confession, 'Ann' explains it would not play a part in her decision to enter into a serious relationship. The suggestion is made that it is 'shallow' to factor the presence of ED into a woman's decision to pursue a relationship with a man. This debate illustrates the morality associated with making such a decision. By viewing ED as a singular condition (that which will inhibit penetrative sex) and by privileging the status of sex in a relationship, a decision to end such a relationship is acceptable. For those like Tina, ED is again framed as a singular condition but in this case penetrative sex is not prioritised with the result that a relationship can be maintained as other forms of intimacy are pursued. In the final posting to this debate, Linda frames ED as the indicator of a greater problem, such as poorly managed diabetes, (for which, according to Linda, the man is to blame). Here, the decision to maintain the relationship is not based solely on the potential absence of sex but on the prospect of a future in which diabetes-related complications (borne out of continued poor glucose-control) such as neuropathy, renal failure and blindness, could be a part of life.

Again the forum offers an insight into how men and women are often concerned with similar issues regarding sex. Some men on the forum have also addressed the issue of maintaining a sexless relationship, in these cases with female partners who are uninterested in sex. The following thread entitled 'I fear I might be developing ED' was started by 'Derek' who became concerned after he developed a problem with his erections. As sex is not a regular part of his relationship he states that it has been difficult 'to test my sexual abilities'. This thread has been viewed 2,792 times and has received 15 replies. The following extracts represent a small sample of the postings.

**Derek**

Well, as for my girlfriend, shes a sexual no go. She hates sex, and apart for a few times a year when she decides that I 'deserve' it for doing something special, Im not getting any action unless I agree to let her drop the pill. It has been discussed a lot, and there is noting for me to do about it. Funny thing though, she did a great job at faking interest in sex right untill I moved in with her and blew my savings on a car, but that is another topic.



[lines omitted]

**Ian**

[lines omitted]

If you can take the advice of a 55-year-old guy who's been over your terrain, if she truly is not interested, leave and find somebody who is. Do some doublechecking in therapy to make sure you're not being a jerk and driving her away but, don't do what I did, don't spend two thirds of your married life or more in a state of semi-celibacy. I would not do it again. I love my partner, I am friends with her but when health problems get in the way of intimacy, it is incredibly destructive and you need to coldly evaluate whether or not you should stay. 30 years is a hell of a long time to be doing it solo style.

[lines omitted]

This exchange exemplifies how the relationship between partners can be affected by disparate attitudes to sex. Here the issue is not the man's ability to engage in sex, but rather his partner's desire. In the original posting from 'Derek', sex is described as a reward which he receives when his partner acknowledges that he has done something to deserve it. Sex happens when an agreement is reached regarding the contraceptive pill. 'Derek' describes his situation as hopeless and his subsequent account of his partner's expressed interest in sex before they moved in together has tones of resentment. His account suggests that his partner's interest in sex informed his decision to move in together. Sex in this case could be viewed as a commodity; it is a bargaining tool which 'Derek's' partner used to encourage co-habiting, reward good behaviour and encourage him to allow her to 'drop the pill'.

The response from 'Ian' shares an insight into his experience of a similar situation. Elsewhere on the forum, 'Ian' explained that his wife suffers from chronic pain and anxiety and this has affected their sex-life. With the power of hindsight borne from his own experience, he advises 'Derek' to end his sex-less relationship. Whilst the issue of being 'shallow' is not explicitly spoken about here, as it was in the previous

extract, 'Ian' refers to 'therapy' as a means to ensuring that the correct decision is made. This advice is given amidst feelings of regret which have emanated from years of a 'semi-celibate' marriage. Ian's response is similar to that of Linda (above) in which the evaluation of one's future informs the decision to maintain the relationship. It would appear that, for Ian, love or friendship alone will not sustain a marriage. However, the 'destruction' of a relationship in these cases is not simply caused by a lack of sex, it has developed from the polarised attitudes to sex present within these relationships and the disparity that results when one's lack of desire to engage in sex (despite having the ability) outweighs another's desire and ability.

Overall, an analysis of the postings on this forum suggest that individual assessments of the importance of sex to a successful relationship, and the framing of ED as either a singular issue or a symptom of a wider problem, inform how men and women respond to the prospect of a sexless relationship. Both men and women emphasise intimacy and the ways in which this can be achieved without penetrative sex; some men and women agree on the importance of penetrative sex to women; while others again share similar opinions on the issue of staying in a relationship where sex is absent. For the majority of postings, men are positioned as the providers of sex and women as recipients; however women are also referred to as having the power to rebuff men's sexual advances. The status afforded to sex within a relationship and the framing of ED, as either a stand-alone condition or a symptom of a greater problem, informs women's decisions about maintaining relationships affected by the condition.

### ***5.1.3 Expressing emotion***

This forum serves as an arena in which men can 'vent' their emotional reactions to living with ED. There is a documented distinction in the literature in the ways men and women express emotion, with men being associated with the containment of emotional expression while women are likely to express emotion with greater intensity (e.g. McConatha 1994; Simpson & Kroch, 2004), and when men do express emotions, they are managed in a way that will preserve masculine identity (Bennett, 2007). A similar distinction has been observed between men and women's emotional expression, in relation to the experience of cancer, in an online environment, with

women concerned with the exchange of emotional support while men are likely to seek medical information (Seale, Ziebland & Charteris-Black, 2006). An analysis of the following extracts challenges these assertions as we see emotions presented in extreme terms by men in their accounts of living with ED.

This extract from 'Andy', entitled 'Men's sexual health' has been viewed 1,174 times and received 2 replies. This succinct message conforms to the general features of online postings from men in that its purpose is to acquire information, but this is followed by one brief sentence which gives an impression of 'Andy's' sense of loss.

**Andy (Extract 18)**

Hi all,

Is there any diabetic in the age range of 60 and still able to enjoy good sex life? Please give me your secrets to a powerful erection. I have lost it all.

Thanks

Here, two factors (diabetes and age) combine to threaten sexual-functioning. Those who are still able to enjoy a sex-life despite the presence of these factors are treated with grail-like appreciation and 'Andy' tries to find out the secrets to the elusive 'powerful erection'. Andy's situation appears hopeless as he has 'lost it all' – a suggestion that in the absence of a powerful erection and a good sex-life, there is nothing. These sentiments are consistent with Gullette's (1998) 'midlife decline narrative' (cited in Potts et al., 2006), and Frank's (1995) 'restitution narrative' in which men view as unacceptable anything but the restoration of their previous sexual-functioning.

This expression of emotion in extreme terms is also apparent in the following extract from 'James' which has been viewed 6,143 times and has received 20 replies. In this case, ED has deprived James of the potential to become a father and he is now losing his confidence as false rumours regarding his sexuality circulate.

**James (extract 4)**

[lines omitted]

my current horrible problem for me is that I am not in a relationship with a woman, never had children cause of the early onset of ED in my life and not having the ability to father a child due to ejaculation problems.

Been told that I am a good looking man and questions as to why I don't have a family, wife, girlfriend etc.

and now, people in my community, co-workers, old schoolmates, old friends actually think that I am gay. I love women, always have and always will.

but the thought of myself going through medical problems such as ED and not being able to have children, and having people spreading false rumors about being gay, is causing me great pain mentally.

I sought counseling before but it hasn't helped me through my severe low self-esteem.

any advice on this excruciating matter?

Unlike the previous posting from 'Andy', 'James' use of the forum in this instance is to obtain emotional support and advice, rather than medical information. He talks about his 'horrible problem', the 'great pain' and 'severe low self-esteem' it has caused him and asks for advice on how to deal with this 'excruciating matter'. These emotions are the result of a threat to his sexual identity. In the absence of a relationship or progeny (which traditionally serve as testament to men's virility) James struggles to demonstrate an acceptable male identity. The expression of emotion is done in extreme terms with the assistance of adjectives that convey intensity. While some research would suggest that this serves to authenticate the account (e.g. Bar-Lev, 2008), it may be the case that the description of such acute and severe emotion legitimises his typically 'non-masculine' expression of emotion. James has illustrated that this is a serious issue ('excruciating matter'), therefore his emotional reaction could be described as rational.

In one of the replies to James' post, Ben shares similar experiences of ED.

### **Ben**

I just became a member and mostly because I've been suffering

with ED for many years now since 1991 to be exact. I married in 1997 and it has been a very difficult because all the drugs viagra, cialis, etc have not worked at all. My wife and I wanted to have children but that never happened. I got to the point that I didn't even want to have intimacy with my wife because I was afraid not to be able to perform and maintain an erection. My starting thinking that I was not into woman, that I was gay because of it and I have told a thousand times that I'm not and how could she think that of me after all the years we've been together (we met in 1990). It has created a total mess in my marriage. I'm at the point to get a divorce even though my wife still wants to work this out. I see no way out of this. I desperate and don't know what to do. I miss my 20's when I was able to have full blown erections and enjoy sex with no problems at all. I thought I was the only one going through and I see how many other diabetic men are suffering from the same complication. Any help or words of advice?

Here Ben makes a link between a successful marriage and a successful sex-life, as the difficulties affecting his marriage have been caused by the failure of medical intervention to restore sexual-functioning. The implications of this have deprived him and his wife of the opportunity to have children and are also threatening his wife's perception of his sexuality. Ben's avoidance of intimacy could be viewed as an attempt to protect himself from the emotional impact of not being able to satisfy her sexually. He expresses inescapable feelings of desperation and despair, and views divorce as the only solution to his situation despite his wife's desire to work things out. As in other extracts there are tones of sexual nostalgia as Ben longs for the ease of youth, when experiences of sex were marked by enjoyment and potency. It could be suggested that being part of this forum has helped to reduce Ben's sense of isolation as he has become aware of how many other men experience ED. Indeed research would suggest that men, like Ben and others on this forum, have an increased risk of depression due to the combined presence of ED and diabetes in their lives (De Baradis et al., 2001).

In addition to seeking advice or support, some postings are made to the forum simply in an attempt to 'vent' emotions as the following posting demonstrates. This message was posted by 'Frank' and entitled 'Here we go again'. It has been viewed 1,061 times and has received 17 replies.

**Frank (Extract 3)**

Hello:

I'm just trying to think positive and straighten my ideas, a lot of tears in the past days. Depression, sensation of guilty, frustration.

[lines omitted].

At this point I'm really frustrated, feel like I can't see the light at the end of the tunnel. My wife is a really nice woman, very supportive and helping a lot to take care of my health but my feelings about not being able to respond in bed when she wants (which is not really often) is frustrating. I know she understands me but I can't stop thinking about my failure. I'm working really hard every day to be healthier just seems is not enough. Some days I keep asking why me? and those moments are horrible, the only thing that keeps me going forward are my two little angels they need me and I want to be here with them as long as I can (I wish until I see my grand kids). My ideas now are like a tornado, I don't know what to do, what to think. I feel so frustrated. I'm sure these feelings are going to vanish in a few days but today I just feel the need to write all this.

Thank you for taking the time to read, I know everybody has his/her own problems.

As in other postings, the overwhelming negative emotions expressed by Frank are borne out of his inability to satisfy his wife's sexual needs and are not linked with a personal incapacity to enjoy sex. The emotions of depression, guilt, frustration and struggle all form part of Frank's experience of life with ED. Kirmayer (1992) describes metaphors as 'tools for working with experience' (p. 335). Here, Frank's reference to being unable to 'see the light at the end of the tunnel' builds an

understanding of his sense of hopelessness – there is no escape from his situation. His account is consistent with what Arthur Frank (1995) terms as a *chaos narrative*. The forum user is 'sucked into the undertow of illness' (Frank, 1995 p. 115). His description of his ideas 'like a tornado' suggest a fluctuant and uncertain psychological state in which despite his attempts to 'think positive and straight my ideas', extreme negative emotions have the potential to overwhelm him causing 'tears' and feelings of desperation that can only be quelled by focusing on his 'two little angels'. Unlike a *chaos narrative*, which 'imagines life never getting better' (Frank, 1995, p. 97), this posting does show some signs of hope as Frank states: 'I'm sure these feelings are going to vanish in a few days'. The forum has provided Frank with the opportunity to express these emotions, something which recent research would suggest is important in terms of men's mental health (e.g. Cleary, 2012).

## **5.2 Discussion**

This study set out to gain an understanding of the issues diabetic men talk about in an online internet forum specifically dedicated for the use of men with the disease. The online forum is increasingly becoming a site of psychological investigation and data from these support-forums have been employed in research looking at, for example, gendered mechanisms of support in online discussions about testicular implants (Seymour-Smith, in press) the fostering of empowerment for people in distress (Barak, Boniel-Nissim & Suler, 2008); gendered differences and similarities between breast and prostate cancer online discussion boards (Gooden & Winefield, 2007); the performance of emotions in an online HIV/AIDs support group (Bar-Lev, 2008); the relationship between participation in a pro-anorexia site and disordered eating (Mulveen & Hepworth, 2006); and discussions of weight-loss and appetite following bariatric surgery (Cranwell & Seymour-Smith, 2012). Yet, aside from Zriebiec et al.'s (2001) study (referred to earlier) very little research has examined the use of online-support groups by people with diabetes, nor have many researchers explored the online conversations of men who are affected by diabetes-related erectile dysfunction.

In this study I found, overwhelmingly, that men and women use the forum as a means to discuss erectile dysfunction and negotiate how their lives are affected by it.

This study has revealed how ED is not just a man's problem, rather, the analysis shows the centrality of the couple to the experience of ED. Research into the couple's experience of life with diabetes-related erectile-dysfunction is considerably lacking. Aside from Schmitt and Neubeck (1985) who found that marriage may suffer if couples do not share an adequate understanding of the linkage between diabetes and erectile-dysfunction, the experiences of this group has been neglected. The study of the couple in other disease-groups (particularly in the case of prostatectomy-induced ED) has received greater interest (e.g. Arrington et al., 2005; Boehmer & Clark, 2000; Botoroff et al. 2008; Mróz et al., 2011; Soloway et al., 2005;). This study, therefore, provides a novel insight into this area and demonstrates the need to attend to the couple's experience of life with diabetes-related ED in both research and treatment.

Men and women are confronted with a number of issues brought about by ED. Both offer differing accounts regarding the causation and treatment of ED, with men focused on external causes and thus artificial treatments compared with women, who often implicate the personal actions of their partners and strive to remedy the problem through changes to lifestyle. Both men and women are concerned with maintaining intimacy in their relationships, and the various ways proposed to achieve this are reflective of individual rather than gendered differences regarding the importance of sex. As the strain of ED takes its toll, both on the individuals and on the relationship, men struggle to deal with the emotional fallout of life with ED.

Men's accounts offer an understanding of the penis as an independent entity. This is demonstrated on the forum by men's use of nicknames for the penis (e.g. 'Mr. Limpy' or 'Mr. Hot Rod') and also in men's accounts of the separate functioning of the penis ('the equipment decided to work'). The term 'dysfunction' or 'function' in itself suggests a mechanical role. The penis is expected to 'function' independently. When erections are no longer achieved the penis is labelled as 'dysfunctional', something which requires repair. Postings to the forum suggests a general acceptance of such mechanical terminology. This mechanical language has received attention in the men's health arena. Gooden and Winefield (2007) note similar terminology in their study of breast and prostate cancer online support groups in which men discuss their frustration at the loss of sexual-functioning and their desire to get the 'hydraulics' working again (p.110). While the references to the male body as a 'machine' have



been identified in research into men and diet (e.g. Gough, 2007; Gough & Conner, 2006) in which men's food choices are designed to satisfy and fuel.

While sexual desires (or needs) are presented as situated *within* the individual (or innate), sexual-functioning is located within the separate penis-sphere and is isolated from such desires. The separation of man and body observed here is consistent with the dominant view of men's sex-drive as a primitive and innate biological force independent of man's logical thinking. Hollway (1981) warns of the dangers of the natural aggression which is accepted in these accounts of male sexuality and how acceptance of this form of male sexuality can contribute to the oppression of women. Potts (2001) considered how this separation (inside/outside dichotomy) impacts on sex behaviours and concluded that by positioning the penis as exterior and capable of it's own thinking ('penis-brain'), men can legitimise or distance themselves from any unsafe sexual practices they engage in.

The separation of man and body was carried through into men's accounts of the causation of ED. In the case of the men in this study, separation facilitated a distancing from the cause of ED and the potential blame which may result from the diagnosis. Here, the causation of ED has been attributed to (amongst others) the use of anti-depressants, the weather, and natural ageing. The mechanical metaphor infiltrates men's accounts of causation and this is demonstrated in a reliance on external interventions to bridge the gap between libido and function, (for example, through the use of Viagra, Levitra, and penile injections). Research into diabetes-related erectile dysfunction implicates poor metabolic control (which is indicative of poor diabetes-management) in causation, (Corona et al., 2004) thus, separating oneself from the cause of ED may serve to be psychologically beneficial as the inability to perform sexually is moved from a personal failing to an uncontrollable external factor. In other cases of disease-related erectile dysfunction, there is no connection between the individual and the cause of ED. For men with prostate cancer, (for example, those who have undergone a radical prostatectomy) the cause of ED can be attributed to the limitations of essential cancer treatment. The onset of ED in these cases represents the logical prioritisation of life over sexual-functioning (Fergus, Gray & Fitch, 2002, p. 314).

However, as we have seen here, for men with diabetes the causation of ED is contested, with those affected by it implicating the culpability of external factors whilst their female partners cite a personal failure to manage diabetes and control blood-glucose levels effectively. Women often reject the proposition that the cause of ED can be separated from the behaviour of the man. Instead these women view poor lifestyle and diet choices as culpable. This viewpoint pushes them into an interventionist role in terms of their partner's diabetes-care where the goal is to improve blood-glucose levels in the hope of improving their own quality of life through the restoration of sex to their relationship. Indeed the presence of women on this forum alone, is indicative of ED as more than just a man's problem. Their presence on the forum highlights not just the importance of sex to them, but also their efforts to assume a recognised role in the experience and treatment of ED. This can be likened to women's attendance at prostate-cancer support groups as observed by Botoroff et al. (2008) in which women assumed the roles of social facilitator, background supporter and cancer co-survivor. It can also be likened to women's traditional role in food provision for partners affected by prostate cancer in Mróz et al.'s (2011) study.

The efforts men and women took to restore sex to their relationships suggests that, for the people on this forum, sex really does matter. A heteronormative construction of sex dominates the postings on the forum; in keeping with what Braun (2000) refers to as 'the taken-for-granted normative nature of heterosexuality' (pp. 133-134). In the context of the forum, 'heterosexuality' is performed in what Braun (2000) would refer to as *heterosexist by commission* and *heterosexism by omission*. Sex is explicitly articulated in terms of heterosexual sex (*heterosexism by commission*), while discussions are also marked by an absence of talk about lesbian, gay, or bisexual sex (*heterosexism by omission*). In many postings from men, demonstration of their male sexuality is reliant on their ability to have an erection sufficient for vaginal penetration. This is consistent with traditional accounts of masculinity. However such traditionally gendered views do not dominate the forum, and this is exemplified in the postings from women who share men's emphasis on penetrative sex and the restoration of 'normal' sexual-functioning. Their accounts are consistent with research suggesting that ED has significantly adverse effects on the female partner's sexual experience (e.g. Conaglen & Conaglen, 2008; and Fisher et

al., 2005) and justify the interventionist approach these women take in terms of their partner's diabetes-care.

For other men and women on the forum, 'intimacy' (achieved through touching, cuddles, etc.) is proposed as the alternative to penetrative sex and is pursued when efforts to restore erectile-functioning sufficient for penetration have failed. Men who propose these forms of intimacy are stepping away from this dominant rhetoric and can be seen as developing a new acceptable expression of sexuality, in the absence of penetrative sex, which serves to protect sexual identity. Potts et al. (2006) study highlighted this approach in older men with ED. The men in their study challenge the post-Viagra emphasis on penetration and accept ED as a normal part of ageing. ED is even seen as a benefit to one's sex-life as it forces one to consider non-penetrative approaches to sex which often result in a greater feeling of closeness to their partner. Indeed some assert that they prefer their post-ED sex-life over that of their pre-ED life.

For the men who prioritise penetrative sex and are unsuccessful in their pursuit of the restoration of erectile-functioning, the forum is used to grieve. The forum provides the space for men to offer vivid and emotionally-charged accounts of their personal experience of life with ED. Women are central to this experience, as men's sense of loss is derived from a perceived inability to satisfy their partner's sexual needs rather than a personal longing to engage in sex for their own enjoyment. In the title of her paper, Potts (2000) referred to the erection as 'the essence of male sexuality' and subsequently noted that 'his perceived failure to erect his penis and perform (with it) according to dominant phallographic notions of healthy male heterosexuality infiltrates his flesh, actions, and thoughts' (p. 85). By viewing erectile dysfunction through these lens, one can appreciate the significant threat it poses to man's sexual identity. Often, emotions are expressed alongside what Frank (1995) refers to as a *restitution narrative*. In these cases men's sense of loss resulting from the demise of sexual-functioning are coupled with a belief that previous sexual ability must be restored and nothing less than that will be acceptable. Similar narratives have been observed by Smith and Sparkes (2004) in their research with men who have suffered spinal cord injury. The significant adverse effect of ED on quality of life has also been evidenced (e.g. Penson & Wessells, 2004) as has the dramatic increased risk of

depression given the dual presence of diabetes and ED (De Berardis et al., (2002), thus, it may be unsurprising that men on the forum offer such emotionally charged accounts of their struggle to cope with a life affected by diabetes-related erectile dysfunction.

That said, such emotional expression goes against the traditional gendered pairing of men with rationality and women with emotionality, and contests much of the literature surrounding gender and emotion. For example, Barrett (2009) refers to the pervasive belief that women are more emotional when compared with men, Polce-Lynch et al. (1998) found in their study of gender and age patterns in emotional expression that adolescent males displayed increased emotional restriction whilst adolescent females showed increased emotional expression. The authors suggest that such behaviour is complicit with socially constructed gender rules in which the expression of emotions may serve to reduce masculinity. More recently, Cleary's (2012) study involving men who had attempted suicide found that dominant masculinity norms had discouraged the expression of emotional vulnerability in these men. Despite feeling significant emotional pain, men constrained its expression and instead opted for suicide.

The conflict between emotional expression and fulfilment of the dominant norms of masculinity has been addressed by Garfield (2010) in a study on how to improve male emotional intimacy in therapy sessions. He found that the values of the therapy setting (disclosure, emotional expressiveness, vulnerability etc.) were incompatible with the traits of traditional masculinity (control, emotional restraint, autonomy etc.). They advise that an 'atmosphere of safety' can facilitate the sharing of feelings. I would suggest that the online forum provides such an atmosphere and thus could be credited for the increased male emotional expression observed in this study. The shared experience of erectile dysfunction establishes the common ground upon which these men form a friendship and the anonymity granted by the use of usernames establishes a safe arena for disclosure. Mulveen and Hepworth (2006) analysis of participation in a pro-anorexia internet site demonstrated how the site was described as a sanctuary or a 'safe place'. Previous research in the field of prostate cancer suggests that physicians are reluctant to discuss the impact of sexual problems with couples, leaving them instead to 'grieve' the loss of this significant part of their

marriage in silence (Harden et al., 2002 cited in Soloway et al., 2005). Here the online forum served as the environment in which men and women affected by ED could open up about this sense of loss .

Alternatively, the intense emotional expression by men in this study may be viewed as an attempt to ensure that their audience deem their accounts credible. Bar-Lev (2008) states that '[b]ecause the meaningful occurrences revealed online cannot be verified, participants must sufficiently anchor their narratives in culturally powerful and socially persuasive texts.....so as to authenticate them and render them credible and valid' (p. 511). The author adds that such accounts 'position themselves and their audience in a unique role, as witnesses to their pain, coping efforts, and entitlement to sympathy' (p. 518). Despite this assertion, other studies have failed to show such intense emotional expression in men online. For example, Zakowski et al. (2003) found greater emotional expression in women with cancer than men with cancer. Sullivan (2003) also explored the area of gendered cybersupport in ovarian cancer and prostate cancer forums. The author noted that women used the forum as an opportunity to 'vent' feelings and obtain emotional support. They noted that men, on the other hand, communicated to one another in highly technical language and it was rare to find postings with dominantly emotive content. While Gooden et al. (2007) did not observe a considerable difference in the frequency of emotional expression in men and women (forty percent of women's communication incorporated emotional content compared with thirty-four percent in men's), the authors did note a difference in the way emotions were expressed with women expressing emotions open and clearly whilst men tended to imply their emotions.

I would suggest, that the expression of negative emotions here was more extreme amongst men who sought to restore sexual-functioning than amongst those who had learned to accept the presence of ED and develop new ways of being intimate. The relentless (and seemingly futile) pursuit of the powerful erection reveals the vulnerability of these men. Distress increases with each failed attempt to perform sexually and fulfil the most dominant demand of male sexuality.

This study has highlighted the wider impact of life with erectile-dysfunction. It has demonstrated that ED is not only an ailment which inhibits men's ability to perform

sexually, rather it serves to separate them from the successful demonstration of their sexuality; for some, it limits their partners sexual satisfaction and in these cases forces their partners to assume an active role in their diabetes-care; it requires men and women to find new forms of sexual expression; and finally it causes significant emotional turmoil for the men who are unsuccessful in their quest to eradicate ED. Both partners in the relationship are held to ransom by ED, and their personal and marital happiness are dependent on the way they address this uninvited presence. These findings serve to elucidate the need to view ED from a couple's perspective and not just from the perspective of the man afflicted by the condition. Some efforts have been made to do this by authors in the area of prostate-cancer research, for example, Boehmer and Clark (2001) have looked at women's experience of prostate cancer in their study which explored the perception of partners' roles at the time of diagnosis and in the treatment decision-making, while Soloway et al. (2005) highlighted the complex needs of the 'prostate cancer 'couple" (p. 4) and the need for psychosexual interventions. However research into couples affected by diabetes-related erectile-dysfunction is still lacking.

In this study the forum acted as a setting in which men could 'vent' and release details of their emotional despair caused by living with ED. Whilst quantitative studies have evidenced a reduced quality of life in men with ED (e.g. De Berardis et al., 2002; Penson et al., 2004.), there is very little qualitative research in this area. The findings here highlight the need for a system of care which not only prescribes chemical treatments to restore erections, but does so alongside attending to the psychological well-being of those affected by ED in a manner which is inclusive of the couple. The linkage between man and body must be restored if the true impact of living with ED is to be appreciated.

The analysis of postings to an online forum has enabled me to provide a brief insight into how men and women are affected by ED. However further in-depth qualitative investigation is required into the issues raised here. Many of the limitations encountered here could be overcome in future research, specifically in face-to-face interviews or focus groups (where the engagement in 'heterosexism' (Braun, 2000) may be challenged by the researcher), or through the establishment of an online forum specifically, and overtly, for use of research in this area. Future research, for

example, could be more inclusive by attending to issues of gay/bisexual couples who may experience diabetes-related sexual problems differently to heterosexual couples (Jowett, Peel and Shaw, 2011). This was impossible to achieve in this study due to the heteronormative discussions on the forum.

### **5.3 Summary**

This chapter provided an insight into how men, and their partners, negotiate the presence of diabetes-related erectile-dysfunction in their lives. The findings illustrate an understanding of man and body as separated, which in turn facilitates men's personal distancing from the causation of ED. Women appear to contest men's account of the causation of ED, citing their partners as involved in its onset. These differing views regarding causation, push women into an interventionist role. Men and women's accounts of the importance of sex were examined. The emotional fallout of living with ED, and the perceived inability to satisfy their partner's needs, is witnessed in men's emotive postings to the forum. These observations were discussed with reference to masculine identity.

**Ch.VI: *'He's got the condition but I've got the problem'*: How diabetic men and their partners balance the management of disease.**

**6.0 Introduction**

While research into the couple's experience of diabetes-related ED may be lacking (as highlighted in the previous chapter), the couple's experience of living with diabetes (both Type 1 and Type 2) has received greater attention in the literature. Such research looks at the individual influence of the partner on diabetes-management, and the dynamics of a relationship affected by diabetes.

With reference to the individual influence of the partner on diabetes-management, studies have highlighted how the communication of support is integral to how such support is perceived. For example, Stephens et al. (2010) found that encouragement strategies resulted in better adherence to the recommended diet while warning strategies had the opposite effect. Similarly, 'nagging' (Trief et al. 2003) is considered to be unhelpful while high levels of expressed emotion (EE) amongst partners (Wearden et al., 2000) were both shown to have detrimental effects on patients self-rated management of diabetes.

Aside from the individual influence of the partner on diabetes-management, research has also looked at the marital relationship and adjustment to diabetes. With respect to couples affected by Type 2 diabetes, Miller and Brown (2005) examined marital interactions in the process of dietary change. Their qualitative study was based on interviews with couples in which one partner was diagnosed with Type 2 diabetes. In total, twenty couples were interviewed (ten couples in which the diabetic partner was female, and ten in which the diabetic partner was male). Their findings suggest three categories of marital adaptation with regards to dietary change: 'cohesive' which represented a teamwork approach; 'enmeshed' which referred to situations in which the nondiabetic spouse was responsible for meal preparation while the diabetic spouse was dependent; and 'disengaged' which referred to the separate functioning of spouses in which each spouse was solely responsible for their own diet management. While to begin, the number of couples identified within each group was 5, 7 and 8 respectively, subsequent to their follow-up study one year later, the



majority of couples were described as ‘disengaged’ while 1 couple remained cohesive and 4 couples remained ‘enmeshed’. The authors point to ‘spousal flexibility’ and ‘communication skills’ as important to the successful adaptation to the diabetes diet (p. 232).

Further research has also pointed to the interaction between the quality of the marital relationship and adherence to the diabetes regimen. There has been moderate support of the hypothesis that a better marital relationship predicts better regimen adherence (Trief et al., 2004), while other research has demonstrated that the marital relationship suffers when spouses disagree over the degree of responsibility each should have over health matters (Peyrot et al., 1988). When taken together, these findings would suggest that agreement between spouses regarding their roles in relation to the management of health, serves to benefit their relationship and adherence to the recommended diabetes regimen.

While these studies give an important insight into the dynamics of a relationship affected by diabetes, there is little gendered research in this area. In each of the studies mentioned, both male and female participants with diabetes took part and gender was not made relevant by any of the authors. Given the centrality of women to their male partners' experience of health-care and illness, as evidenced by the literature considered in Chapter 2, it is surprising that research has failed to attend to the experience of couples in which the male partner has Type 1 diabetes – a disease which by its chronicity, shall always be present in the couples lives.

In this chapter then, I consider the familial experience of living with Type 1 diabetes, as informed by a group of diabetic men and their female partners. As with the previous studies detailed in this thesis, I utilised a Grounded Theory approach to the analysis of the data (as detailed in Chapter III). In line with my approach to the study detailed in Chapter IV, I wanted to afford couples the opportunity to reflect on their experiences of diabetes over the years. I did not want them to be restricted in their accounts by the parameters of the interview schedule and so I kept the questions broad, enabling the participants to direct the flow of the interview. The GT methodology facilitated this approach as it recommends that the researcher begin with a general research question which then narrows around the emerging analysis.

In this chapter I shall detail the findings of this analysis and what these findings contribute to what we already know about the couple's experience of diabetes.

## 6.1 Analysis

Analysis of the data resulted in the identification of two spheres of diabetic life: *overt diabetes* and *covert diabetes*. These spheres of diabetic-life, when taken together provide an understanding of how men and their partners experience life affected by chronic illness. The *overt* sphere of diabetes represents the day-to-day management of the disease and illustrates how couples incorporate the management of diabetes into their lives through varying levels of reliance. *Covert* diabetes refers to the sphere of diabetic-life which is not visible. Confined to this sphere are the concerns and worries raised by the long-term presence of diabetes. A lack of communication between partners serves to perpetuate the separateness of this sphere.

### 6.1.1 Overt Diabetes – Negotiating roles and reliance

In the *overt* sphere of diabetes, the roles of men and their partners in the management of the disease are determined by the level of reliance they place on one another. I identified three management styles: resisting reliance; sharing 'self'-management; and picking up the pieces.

#### *Resisting reliance*

In the case of couples who used this approach to diabetes-management, the male partner placed minimal reliance on their partner for assistance in the management of their diabetes. Rather, they tried to contain or limit the input their partners had. In the extract below, Glenn makes efforts to minimise the role credited to his wife. This particular extract followed a discussion about Glenn's most recent check-up in which he, and Deirdre, were informed of the development of complications with his retina.

#### Glenn and Deirdre: (50-72)

D: I do cook quite healthily, I mean I make all my chillis from scratch, I don't use jars for anything and stuff like that

**I: yeah**

D: so I know that he's eating quite healthily here but I have a friend in the office where he works and she says that he attacks the biscuits like there's no tomorrow, so he's caught there now as well so this is the first time that it's actually kind of,

**I: yeah**

D: so I'm a little bit wary of that, so I'm probably, I'd be more strict on him than he probably would be himself, I think, would I?

G: well yeah, it's an excuse to nag isn't it ((laughs))?

[lines omitted]

**I: and Glenn do you think that em, like Deirdre is the person who is controlling the diet?**

G: ((pauses)) well, em, I suppose from a food preparation point of view, I suppose she is

**I: yeah**

G: but as far as managing it goes, then I obviously have to manage the blood-sugars and what not so em, I, well I suppose you do most of the cooking

D: and I make your sandwiches and everything so I know what goes in there

G: but you don't sit down and calorie-count it or anything

D: no

Similar to the interventionist role of the women in Chapter IV, here Deirdre positions herself in a supervisory role when it comes to Glenn's diet. Under her watch, he eats healthily and this is thanks to the effort she makes to prepare all food from scratch and also to her 'strict' approach. Outside of the home, however, Deirdre has learned that Glenn is undisciplined. She refers to him as being 'caught', as she is made aware of his indulgence in biscuits while at work. Based on Deirdre's account, Glenn would appear child-like and weak-willed, and therefore she has taken the necessary steps to enforce discipline. While Glenn does not contest this account, he does suggest that Deirdre uses her position as an excuse to 'nag'. Glenn goes on to confine her role in the management of his diabetes to 'food preparation', giving little recognition to the steps involved in 'food preparation', and limits it further by stating

that she does not 'calorie-count', thereby making her role less specialised. His repeated use of the word 'suppose' and his pause before answering could be viewed as a reluctance to acknowledge her role, and this is in contrast to the certainty with which he asserts his responsibility for management of blood-glucose levels ('obviously'). Indeed, Glenn foils Deirdre's attempts to claim a role in the management of diabetes: his counter-statements ('but as far as managing it'; 'but you don't') serve to contest Deirdre's account and eventually she concedes defeat. The responsibility for management of blood-glucose levels is most certainly his and this out-weighs Deirdre's limited contribution to dietary management.

Similarly, for Ben and Fiona (below) the *responsibility* for management is retained by Ben as he has learned not to rely completely on Fiona.

Ben and Fiona (73-90)

**I: so when you are going out and about for the day, who remembers all the diabetes gear?**

F: we both do really

B: yeah but I like to pack it myself

F: yeah he does, and then he puts it in my handbag ((laughs))

B: yeah but there's no winners if I say 'you pack it' and then there's something missing, you know, there's no

F: yeah I know

B: and I think it's happened before

F: that I've packed it?

B: it needs, it needs to be my responsibility

F: that I packed it and there was something missing?

B: yeah

F: really?

B: yeah and there's no winners when that happens

F: are you a bit bitter about this?

B: no no, no I'm not but there's just, there's no em

F: yeah, yeah, I suppose I kind of remind him to do it but he'd remember the needles and the strips and all that

As evident in Glenn and Deirdre's account, earlier, this extract illustrates a battle between Fiona and Ben to assert their individual accounts of management roles within their relationship. Despite Fiona's initial assertion that both she and Ben are involved in the organisation of diabetes equipment, Ben is quick to contest her statements ('yeah but') and to position himself as having ultimate responsibility for this task. This is the way it 'needs to be' in order to avoid instances of items being forgotten. Fiona appears to be learning about these defined roles throughout this dialogue and as her role is under threat of confinement, she reinstates her position in the organisation of diabetes-equipment by stating that she reminds Ben to pack everything. Both Fiona and Deirdre are forced to concede their initial determined positions and accept a more peripheral status in diabetes management: preparing food or giving reminders.

What is evident in these accounts is a disparity between partners regarding the extent of the female partner's role with regards to diabetes-management. Deirdre and Fiona claim involvement in their partners' regimen but both Glenn and Ben refuse to depend on their partners to assist in the management of their diabetes. Instead, they maintain responsibility, and thus control, of the management of their disease.

In the case of Jack and Clare (below), both of whom have had Type 1 diabetes for in excess of forty years, the individual management of diabetes, rather than a shared familial approach is natural, as the following extract illustrates:

*Jack and Clare (lines: 383-387)*

J: so like Clare sorts out all my other tablets cos I'd get confused with all of them but not my diabetes, definitely not.

C: but I wouldn't want someone trying to tell me what I should be having and doing

Here Jack's reliance on Clare is to assist with things other than diabetes. The tablets which she sorts out relate to other health conditions. He owns his diabetes ('my diabetes') and therefore is solely responsible for it. Clare shares these sentiments with the suggestions that the input of someone else into her diabetes-management would be an unwelcome intrusion. Perhaps Clare's 'insider' experience of diabetes

has informed her position. Unlike Deirdre and Fiona (above), Clare has first-hand experience of living with diabetes. As such, Clare respects the boundaries of Jack's diabetes-territory, as she would expect the same in return. Thus, diabetes is *personal*, it is a possession, and it is the sole responsibility of the individual with the disease. Ownership is protected by resisting reliance on others whilst delegating certain, limited, management-tasks (for example, food preparation).

In cases such as these, a reluctance to *allow* one's partner to command an established role in the management of diabetes can be viewed as an attempt to preserve personal control. This is in keeping with the findings highlighted in Chapter IV, in which men's personalised approach to the management of diabetes (which facilitated the achievement of personal goals) was viewed as the product of their overarching desire to retain control of their lives by controlling the presence of diabetes. Jack explains this further in the following extract as he discusses his possessiveness over *his* diabetes.

Jack and Clare (lines: 364-372)

**I: Jack do you think that Clare has a role in your health? Or that she takes part in trying to keep you healthy?**

J: sure, she tries yeah ((laughs)) that's a fair comment is it?

C: yes, I do try

J: I do listen sometimes

C: mmm

J: yeah, yeah, but I control it myself all these years and I still want to control it. I hate the point like, when I'm going into hospital like the eye operation and the hand operation, being put out, hate being out of control, not knowing my destiny

**I: yeah**

J: because however good they are at the hospital, they don't get it right when you've come round and when you're trying to control your diabetes, they won't give it back to you to control straight away, which you know is the best policy because they get it wrong.

The opening exchange demonstrates that Clare has attempted to play a role in Jack's

health care, more generally, but these attempts are not always successful. Jack treats diabetes like a treasured possession and he, like Ben (above), must protect this possession from the potential mismanagement of others. In this case, his personal expertise, borne out of living with diabetes for so many years, is privileged over that of healthcare professionals who can 'get it wrong'. Indeed the healthcare scenario is the arena in which Jack experiences the most pronounced struggle to maintain power over his diabetes and, ultimately, control over his 'destiny'. Being out of control, here, is presented, on one level, as being anaesthetized ('being put out') but also with having the opportunity to control his diabetes removed from him.

In each of these cases in which the management of diabetes is marked by a resistance to rely on one's partner, men attach priority to the decisions involved in the holistic management of the disease, whilst the practical activities of management assume a lesser status. In this way, carrying her partner's diabetes-equipment or ensuring that her partner has healthy meals available to him, represent a limited contribution of management. The next section illustrates how for some couples, the practical activities to management receive greater recognition.

#### *Sharing 'self'-management*

In the case of couples who strive to maintain a balance in their relationship, sharing the management of diabetes helps to achieve this. For James, below, sharing management of diabetes is a logical step as he explains that the multitude of items that need to be remembered in order for diabetes to be managed effectively is too great to deal with alone.

##### *James and Glenda (lines 185-191)*

J: I think it's, I think it's joint because you couldn't possibly hold it yourself, you know it can't just be my thing you know, as much as I would like it to just be my thing because that's the way I've always approached it, you can't possibly do that, you've got to share it out and I suppose everytime we're having dinner, what time it's going to be at, have I an injection done, will I do a test before it, it is, just you know going for a walk, bring the testing kit, bring the sugar,

you know get all the stuff organised I don't think it's possible that I just have it, and I wonder then is it just because we share everything, because we know each other so well.

Here, as above, the management of diabetes is treated as a possession, something which despite his best wishes he is unable to keep to himself. By moving from 'I' to 'you' in his account, James normalises his decision to share his diabetes with his wife as what anyone would need to do ('you've got to share it'). By listing the extensive requirements of this possession, James justifies his decision to share diabetes-management with his partner, as no doubt these requirements already impact on her life in some way. While the decision to share the management of diabetes may be forced upon him by the extensive requirements of the disease, it seems it is a natural fit in their relationship as they already 'share everything'. One could suggest, therefore, that the existing dynamics of the relationship determine whether the duties involved in the management of diabetes will be evenly balanced and shared by the couple. By sharing the management of diabetes, James and Glenda make a combined effort to manage diabetes, with Glenda prepared to make up for some of the skills which James may lack:

*James and Glenda (lines 56-67)*

G: God love him, he's a little bit absent-minded ((laughs)) and I get frustrated with his absent-mindedness about something that is such an intrinsic part of him you know, so there have been times where he has gone out without his testing kit, he's forgotten it, now they're rare but I can't wrap my head around that, I can't understand how you could forget something that is so necessary to you or you'd go, the odd time he'd go out without an insulin pen or not enough to carry him through the meal and then I'd be watching him like a hawk through the meal and you know, 'come on we have to go soon' or 'you can only eat a little bit there' or he's not enjoying the meal and therefore I'm not enjoying the meal and that kind of thing, and I would get incredibly frustrated that he would leave and not remember something as basic as your insulin, and it's the same as carrying sugar around so I've started doing that, I carry sugar



around, I carry an insulin pen and this kind of thing ((laughs))

Glenda's involvement in the management of James' diabetes means that she can compensate for his absent-mindedness. In her account of doing so, she sometimes positions James as child-like, particularly when they are out for a meal as she supervises his food-intake and tells him when it is time to go home. In sharing in the management of diabetes, Glenda also shares in the fall-out of occasions where James has forgotten essential items of his diabetes-equipment: 'he's not enjoying the meal and therefore I'm not enjoying the meal'. Having learned from, and been frustrated by, these occasions, Glenda now prepares for these eventualities by bringing her own supply of these items. This approach not only serves to benefit James and his diabetes, it also allows for equal enjoyment of social occasions. Glenda's attentiveness to the demands of diabetes serves to preserve the normality of these occasions for both of them.

As Glenda established her role in the management of diabetes by learning what was necessary in order to provide a comprehensive team-approach, Louise (below) learned what was necessary to protect her equality in their relationship. The following extract explains how she resisted the role of carer by inhibiting Brian's reliance upon her. In doing so, she empowered her husband take control of his diabetes.

Brian and Louise (lines: 16-43)

L: I got to know about how to, for lack of a better expression, look after him through his parents em, so, when he did have some quite bad hypos then em, I learned how to inject him with glucagon and things like that because his parents were there which is quite a different situation to if he had been living on his own or or whatever, em, but on the other hand I did get your parents and your families perspective of it and I think we've [changed]

B: [yeah]

L: slightly how we deal with things since then I think

B: cos they look after me, they always look at me as their son, brother and whatever and Louise has taught me to look after

myself, which is very different.

L: so if he had low blood sugar, even if he was fine and not having what I would call a proper hypo, em which is most of the ones he has where he is just a bit low but he is still able to look after himself,

**I: yeah**

L: his parents would run and get him a glass of orange juice or whatever and look after him, but I say well okay go and get yourself a glass of juice because he is capable of doing it, and I think that em, he, I just felt he needed to be a bit more independent if that makes sense

**I: yeah**

L: and it felt a bit mean to start with but I thought well when we're living together and not with your parents, and I have to go away somewhere like for work, I can't be scared that you as an adult can't look after yourself, even that sounds awful cos he could look after himself but his parents would do it for him

**I: yeah**

B: and frankly that's helped me more than anything else with the control cos I actually took charge of my own diabetes whereas previously I had kinda, I'd wait until someone said 'are you low?' and then I'd do a blood test and grab something to eat whereas now I pro-actively test my bloods and keep my own eye out for low blood sugars and stuff which I just didn't notice them before

Previously, Brian did not prioritise having personal control and responsibility for his diabetes. He did not contest his family's involvement in his care in the past, rather he normalises it. However, he has been open to the empowering presence of Louise with regards to his care. What is apparent is Brian's growing sense of responsibility for the management of his diabetes.

Louise's account illustrates how Brian's approach to the management of his diabetes has evolved from him being the passive recipient of his family's care, to being an active agent in the management of his disease. Indeed, this is reflective of the

findings in Chapter IV, which detailed how men's relationship with diabetes is open to flux throughout the lifecourse, and with it comes a changing approach to the management of the disease. Previously, Brian's family held possession of the responsibility of diabetes-management, something which Brian suggests as a natural familial role. With Louise's intervention, the responsibility for management of diabetes was given to Brian for the first time. Brian credits Louise for 'teaching' him how to manage diabetes independently. The change in management styles was not forced upon him, as Louise explains 'we've changed' and 'we deal with', illustrating her view of management as a team-effort.

Louise's successful intervention allows her more freedom, as she explains that she can leave the home without the worry that Brian is not capable of taking care of himself. Most importantly, by preventing Brian's reliance on her, Louise protects herself from the imposition of the role of 'carer' and in so doing, maintains the equality in their relationship. This, as she explains in the next extract, was a very intentional result:

*Brian and Louise (lines: 69-71)*

L: I wanted us to kind of be equal in everything really and that meant that I wasn't going to be in charge of looking after him without him also looking after himself, em so yeah I think it was pretty much a conscious effort really.

For Louise, equality in the relationship is maintained by the shared participation in the management of diabetes. She is prepared to care for Brian but only if he is also prepared to care for himself. This management style of *sharing 'self'-management* has benefits to both partners in the relationship. It serves to preserve the normality of life for female partners while also giving recognition to the role they play in the management of diabetes. At the same time, it allows male partners to benefit from a comprehensive system of care (in which individual strengths and weaknesses with regards to management are balanced by a team approach) while also relieving them of some of the demands of diabetes management.

### *Picking up the pieces*

The previous category of management style illustrated the mutual benefits of a shared approach to the management of diabetes. By contrast, the category of 'picking up the pieces' accounts for those relationships in which the female partner is relied upon to facilitate the male partner's preferred approach to diabetes management. In these cases, female partners appear tasked with the physical care of their partners whilst the male diabetic maintains responsibility for the way their diabetes is managed. The following extracts illustrate this relationship and its tensions.

#### *Aiden and Caroline (lines: 79-83)*

**I: how would you say life changed for you when the diagnosis came?**

C: my world ended ((laughs)) didn't it?

A: yeah

C: I wouldn't go anywhere, I was always worrying about him. I always say, he's got the condition but I've got the problem.

Caroline's reaction to Aiden's diagnosis may be similar to that of someone who had personally been diagnosed with a chronic illness. While she may joke that her 'world ended', there is no question that her life changed considerably as she became trapped by her own worry and feeling of responsibility for Aiden. As the interview progressed, Caroline explained the role she plays in the management of Aiden's diabetes and likened it to that of a carer. The following extract illustrates how this role is played out in daily life and also gives an insight into how their relationship has been affected by it.

#### *Aiden and Caroline (lines: 251-292)*

**I: Do you see Caroline as a carer?**

A: ((laughs))

C: ((laughs))

A: yeah I suppose so

C: oh yeah he kills me cos I'm always nagging

**I: yeah?**

C: cos I say if Aiden didn't have diabetes we'd be perfect, cos that's the only thing we really argue about

A: yeah

C: like thank God we don't have much time for arguing we get over it anyway

A: it does put you in a bad mood doesn't it?

C: I get in a bad mood because I think he's done it again and if he cared about me he wouldn't let himself get like that, talking to myself, and I stop talking to him

**I: so you take it personally?**

C: yes

**I: and, well I'm guessing there's no intent?**

A: yeah but she's in a bad mood then for the rest of the day and I don't know why ((laughs))

C: he thinks 'well you know I've got diabetes, you know I'll get like this' but there's no need for, he'll be down the garage and he's mad into fiddling with everything, taking things apart and putting them back together and ((sighs)) it drives me nuts, and that's a stupid thing he's doing and he won't even look up at the clock

A: but that's something that's built into me

C: he has two clocks in the garage and he won't look up and think 'oh I should be eating something'

**I: yeah**

C: and I keep my fruit and everything down there, and there's bananas down there and everything he needs he can get at, mars bars, bottles of lucozade, cos I have them everywhere

**I: yeah**

C: and he wouldn't even dream of doing it. But I resent that he thinks that I'm his mother

A: ((laughs))

C: I have to go down and say 'Aiden, it's time [you were eating]'

A: [time you were eating]

C: and I still have to go down again, and maybe three times, and I

know I'm doing it wrong, his cousin says I'm doing it wrong, 'let him have a big hypo it'll frighten him', but it won't

**I: do you feel that having Caroline around is like a security-blanket, it gives you a license to forget about it and get on**

A: yeah it lets me get on with my job better, whereas if I'm on my own here I seem to take more control because I know there's no one going to come and help me

**I: yeah, would you be nervous about being on your own**

A: em, no no not really no, just make a couple of adjustments I suppose

C: so why can't he do that when I'm here? That's what I want to know

A: well when you are here I feel that I've got more freedom, but if you weren't here I'd feel that I'd all the time have to be doing my tests, I'd have to make sure I was higher I suppose.

While I asked Aiden if he saw Caroline as his carer, to which he hesitantly agreed, it may be more accurate to position her as the 'by-proxy diabetic'. When Caroline is present, the responsibility of diabetes is placed upon her. She is the one who is mindful of eating times and ensures that necessary supplies are ever-available for the treatment of hypos. Aiden's reliance on Caroline has endured despite her 'nagging', their occasional arguments, and her maternal-like presence, because of the value he has attached to the freedom achieved through this reliance. She has created an environment for him within which he can forget about managing his diabetes and invest his time and energy in the things he enjoys, like 'taking things apart and putting them back together'. While Aiden may make the argument that concentrating on his work to the detriment of his diabetes is 'built-in' to him (perhaps by virtue of being a man), the deliberate adjustments he makes to his care while Caroline is not at home, would suggest that his management style is intentional rather than natural.

Aiden attaches priority to being able to 'get on with [his] job', and this priority informs the extent to which he follows the recommended care-regimen. This approach compliments the findings highlighted in Chapter IV, in which the pursuit of the goal of 'working hard' inhibited adherence to the recommended care-regimen.

Instead of stopping to check his sugar-levels, Aiden immerses himself in his world of work and passes the responsibility of diabetes to Caroline. When Caroline states *'he's done it again and if he cared about me he wouldn't let himself get like that'* she is referring to Aiden falling into a state of hypoglycaemia, something which Caroline feels could have been prevented if he remembered to eat on time or stop and check his blood-glucose levels regularly. While Aiden makes the claim that hypos are a feature of the diabetes, Caroline takes it as a personal disregard for the burden hypoglycaemic events place upon her. It is the burden of Aiden's particular approach to disease-management which Caroline is forced to deal with. Had she been granted entire responsibility and 'ownership' of diabetes, Caroline would be in a position to intervene in the level at which Aiden maintained his blood-glucose levels, thereby minimising the amount of hypoglycaemic events. She has, however, been denied this access and instead is forced to pick up the pieces of Aiden's management style. Ultimately, Aiden has the power to control his diabetes as he wishes and his reliance on his wife ensures that this control is safely achieved.

For Jack and Clare, below, whilst the management of diabetes may not be shared, living life with the effects of diabetes-related complications forces Clare to assume a role in Jack's care, albeit not necessarily the care of his diabetes.

*Jack and Clare (lines: 723-725)*

C: I'm always aware that I can't go too far, I have to be here, I have to wash and dress his feet, if he falls over I have to call an ambulance you know, that that is quite a big thing to deal with.

Like Caroline, above, Clare's life is restricted by her husband's medical condition, the responsibility of which is a 'big thing to deal with'. Her account gives a sense of being psychologically burdened by a sense of responsibility for her husband. This responsibility has been forced upon her; suggested by her repeated use of 'I have to'. Jack has suffered from numerous complications associated with diabetes. He told me that he has no feeling in his lower legs and he also advised me that he has problems with his shoulders. His stomach no longer contracts properly and he has recently had four operations on his eyes to address haemorrhaging, a detached retina and cataracts. For the most part, Jack is confined to a wheelchair or mobility scooter. I

asked Clare how she felt her role has changed since Jack developed these complications and if she saw herself as a carer.

**I: do you think your role has changed since Jack has got the more serious complications with his feet, have you ever felt that you've become a carer?**

C: yes

**I: and would you see Clare in that light?**

J: oh she is, yeah

**I: do you ever resent that?**

C: yes

**I: can you talk to me about that?**

C: ((laughs))

**I: only if you want to**

C: em, I suppose it's part of this feeling that he's brought it on himself, and eh, he has a high alcohol and a high fat diet which I think doesn't help and, and when he asks me to get things and do things for him I quite often say to him eh 'use it or lose it', and you know I do resent that quite a bit.

Clare hesitantly confirms that she resents the role of carer which she has found herself in since Jack's more serious complications have come about. While she may not be involved in the management of his diabetes (as explained earlier) she is left to pick up the pieces of his own healthcare decisions. His current physical state, she sees, as a reflection of his poor diet and high alcohol intake; not only has 'he brought it on himself' but he has also brought it upon her. Her frustration is borne out of his reliance on her, particularly when she feels he could do more to care for himself.

The resentment in both Clare and Caroline's accounts is borne out of the role of carer which has been forced upon them, seemingly with their partner's intentions. As Aiden admits, above, he could manage his diabetes differently if Caroline were not there, however he chooses to pass the responsibility to her in order to free himself from the constraints of disease. In the case of Jack and Clare, the resentment is borne out of the presence of, what Clare views, as self-induced complications. This



attribution of blame to the individual with diabetes, as opposed to the disease itself, is similar to how women in the previous chapter explained the onset of ED in their partners, and as in that study, this causation is contested here by Jack:

*Jack and Clare (lines: 267-274)*

**I: you said you can see what Jack has done to himself, do you see the complications as something that's brought on yourself or is it because of diabetes?**

C: probably feel that he's brought it on himself, [I suppose]

J: [yeah but]

C: probably shouldn't but I do

J: yeah but if I weren't a diabetic would I have these complications? No, I don't think I would

C: well no

J: so ((pauses)) would have had a heart-attack and died by now ((laughs))

As both Jack and Clare have lived with Type 1 diabetes for in excess of forty years, it is interesting to note their conflicting beliefs about the causation of complications. Clare blames Jack for causing these complications but appears to feel uncomfortable voicing this blame ('probably'; 'suppose'). Jack, on the other hand, externalises the cause of these complications to diabetes rather than accept personal blame. Specifically, Jack equates *being* a diabetic with the presence of complications. By implicating the unavoidable diabetic identity, rather than his agency in the management of diabetes, Jack positions himself as naturally vulnerable to complications. Jack's present complicated physical state was predetermined at the initial onset of this autoimmune disease. By joking that without diabetes he would have died of a heart-attack by now, Jack lightens the seriousness of the discussion but also implies his agency in the positive management of the disease: having diabetes has forced him to make healthy dietary decisions over the years.

### ***6.1.2 'Covert Diabetes'***

The 'overt' sphere of type 1 diabetes deals with the practicalities of disease and the

way it is incorporated into daily life. The 'covert' sphere on the other-hand is concerned with the less visible aspect of diabetic life. My analysis suggests that confined to this sphere, are the worries and concerns of the individuals affected, both directly and indirectly, by diabetes. The lack of communication between partners about these concerns serves to perpetuate the separation of these spheres of diabetic life and also confines worry to an individual, rather than shared, burden.

### *Managing worry*

Throughout the interviews, 'worry' is treated as something personal and not shared. It is something which is confined to the 'covert sphere' of diabetic-life in order to prevent its intrusion on daily living. By managing worry in this way, those affected by diabetes can preserve the normality of their lives.

In this extract from Ben and Fiona, worry is positioned as something which makes an occasional intrusion into their individual lives ('sometimes', 'the odd time') but never receives the greater attention of the couple:

#### *Ben and Fiona (lines: 135-149)*

F: sometimes I kind of worry about what happens like, what can happen as we get older you know

**I: yeah, is that something you talk about?**

F: no

**I: and what would you worry about?**

F: oh I don't know like, I just, worry that maybe things might start happening to him because of his diabetes as opposed to somebody else in their fifties you know, but no I don't really ponder on it for long but it, it occurs to me the odd time like, I'm sure it occurs to you as well, but actually it's funny, we don't talk about that at all, like we talk about later in life but we don't talk about, you know, that element of it

**I: do you make an effort not to talk about it?**

F: well I don't think it's the elephant in the room, I think we're both like ((laughs)) well we're chilled out people

B: well there's nothing to gain by worrying about it, all you can do is manage it well now

F: yeah so main thing is to prevent certain things happening

Here, worry is manifested by thoughts about potential diabetes-related complications. Fiona manages the intrusion of worry by situating these complications as far off and therefore not relevant to the present. She also treats complications as hypothetical: '*things might start happening*' and perhaps it is this viewpoint which results in the omission of their diabetic-future from their discussions of later life. While Ben asserts that there is nothing to be gained by worry, I would suggest that worry, to any degree, serves to focus energies on the management of diabetes in the present in the hopes (as Fiona states) of preventing '*certain things happening*' in the future.

For Deirdre, in the following extract, worry is managed by deliberately avoiding information about complications.

Glenn and Deirdre (lines: 566-576)

**I: I think I've covered pretty much everything, is there anything else you would like to add?**

D: Em, no I don't think so

G: unless you [directed towards Deirdre] want the list of potential complications ((laughs))

D: no well half the time I stop reading because I don't want to know them

**I: yeah**

D: and I think if I did know that's something that would really worry me so, if

G: so you're in denial then are you?

D: a little bit, if ((laughs)) anything does happen you just deal with it and that's the way I'm looking at it.

Here, perhaps, through engagement in an interview with her diabetic husband and a diabetic interviewer, Deirdre had the opportunity to gain information about the 'list'

of possible complications associated with diabetes. However she chose not to obtain such information so as to protect her from the worry borne out of this knowledge, and this – as she explains – is a tactic of managing worry which she regularly employs. Accepting that this could be seen as 'denial', her sentiments could be likened to Ben's (above) in that there is nothing to be gained by worry and rather should something happen in the future, they shall deal with it then. Worry is therefore, managed by avoidance and by relevance; the sources of worry are confined to the future and thus their emotional impact on the present is restricted by avoiding information about complications.

Louise (below) offers a similar account of managing worry in which her focus is on the practicalities of the present. Her husband, on the other hand, appears burdened by worries of potential complications in the future. Their account illustrates a division of worry between partners.

Brian and Louise (lines: 217-258)

B: I think we probably have different sorts of worries, you you worry about me hurting myself or other people or whatever and I, I think most of my worries are based around things like complications and stuff

**I: Mmm**

B: which are another of those things which are just always there and you constantly think about them because it's going to happen really, there's no way it won't happen

L: You see I don't ever really worry about you long-term or think about it

B: no so yeah, it's just different [different]

L: [it doesn't ever occur to me]  
((laughs))

**I: why doesn't that ever strike you, why are there different types of worry?**

L: I don't know really, I guess em, I don't know, I mean you would occasionally talk about, when you've been to your consultant appointment, your annual one, em, and you might talk about what

happened there or you are on those tablets now because of you

B: protein, no it wasn't protein it's

L: no you said it was ketoacidosis but that wasn't right it was your kidneys

B: oh yeah it was proteins yeah

L: em, and so you talk about what that might mean and we read about other complications that people have had like blindness and kidney disease and whatever but, I don't know, I just, em, it's not that I don't think Brian will ever have it, but it doesn't equate with, I just don't see it, I just don't think of it happening

B: I think, I think you worry about the visible things, I worry about the psychological things, sort of not psychological

L: internal stuff, yeah, I don't know yeah it's not, it's not that I don't think that will never happen to you, I'm not completely stupid, I'm not burying my head in the sand but I don't see our future together and see Brian on a dialysis machine whereas I don't know, do you, or do you worry that it might happen?

B: I worry about it, I don't, I don't imagine it

L: yeah, maybe I think I'll worry about that when it happens. Cos lots of things might happen to you

B: yeah like getting run over by a bus

L: ((laughs)) no, well lots of complications might occur so whether its that I don't know about them all or whether I just don't know what I should focus on, I I just don't think of it basically, that's the simple answer

B: yeah

**L: Is it reassuring for you to know that Louise isn't overwhelmed by that kind of worry?**

B: yeah, because if she worried about that stuff she'd go mad really

L: ((laughs))

B: because the only reason that I have to worry about it is cos, I, I, I have to have concerns about it because it gives me a bit of a fire in my belly to cope with my diabetes really, to make sure that I've got the best control that I can possibly have whereas she doesn't

need to think about it and, I'm glad she doesn't cos it would just upset her because it's not important really at the minute

L: it's not a nice thing to imagine

B: no it's not

There is an inevitability associated with Brian's construction of diabetes-related complications (which could be likened to Jack, earlier). As opposed to seeing them as 'potential' he refers to them as a certain part of his future life. This certainty is perhaps the reason for the relentless presence of worry Brian currently feels in his daily life (*you constantly think about them*). He is unable to confine complications and their worry to the future, they are very much a part of his present. But even this incessant presence of worry can be viewed in a positive way as Brian explains that it gives him the focus required to keep his blood-glucose levels under control. Unlike Louise, worry has a purpose for him, as ultimately the responsibility of diabetes-management lies with him.

While Louise is aware of the potential complications associated with diabetes, and is prepared to discuss these complications when needs-be (for example, when Brian started medication for the treatment of proteinuria which is an indicator of renal damage), she is not affected by worry. This may be because, unlike Brian, worry serves no purpose to her. It may also be because the plethora of complications associated with diabetes means that to worry about the possibility of each one occurring is impossible, so she chooses not to worry at all.

### *Revelations*

Despite making attempts to keep the spheres of diabetes separate, there are occasions when an individual's 'covert' world of diabetes comes to light, resulting in surprising revelations for their partner. For Brian and Louise (below), these revelations came about following the birth of their son:

#### *Brian and Louise (lines: 87-117)*

L: when we had the baby, I said to you would you mind, you know, if he got diabetes and your reaction was really strong

B: yeah

L: and you said 'I'd hate it, I'd absolutely hate it', and I thought that's so bizarre because we don't let it

**I: yeah**

L: you don't let it affect your life

B: yeah

L: it doesn't, well anymore than it has to, em so I thought that you would say 'well I'm okay, I've survived, it's alright blah blah blah', but you were so strong against him, you know you would hate it if he'd got it, not because Brian feels responsible but because he would just hate to think his son was going through that

**I: yeah**

L: I'm actually getting emotional thinking about it ((laughs)), because yeah it's just, yeah I didn't imagine you would say that

B: yeah

**I: why would you hate that?**

B: because it's horrible frankly,

**I: yeah**

B: it's not something you'd wish on anybody especially, your own child cos, you, until you've got one you don't realise quite how strong your feelings are for them so you don't want anything bad to happen and I think diabetes, although it's, it's not the worst thing that you could get there's much worse things

**[lines omitted]**

B: and there's all sorts of horrible diseases and you just, but diabetes is one of them, no matter how you look at it it's a fairly horrible thing to have

L: and it's constant and always [there]

B: [it's forever] or at least at the minute it's forever until they sort something out in another thirty years time most likely.

Brian's reaction to the possibility of their son being diagnosed with Type 1 diabetes came as a surprise to Louise because it contradicted her understanding of how they

experienced life with diabetes. Whilst, in her view, they (or Brian) were able to live a life where diabetes did not have a major effect, this belief does not compliment the 'horrible' picture Brian paints of the disease. Whilst their lives may, overtly, be unaffected by diabetes, in the 'covert' sphere of diabetic life its relentless presence looms large for both partners.

In the case of Ben and Fiona (below), Ben's concerns that his daughter may develop Type 1 diabetes were not voiced until participation in the interview.

*Ben and Fiona (lines: 408-428)*

**I: when you were pregnant, did you think about or wonder if she could get it?**

F: no I didn't think about that at all. Did you think about that before we had a child?

B: em yeah,

F: but you didn't discuss it with me of course

B: ((laughs)) well there's no point like, it's just a percentage chance you know what I mean, I I would be kind of like no, it's just the kind of thing you don't ever want to talk about when you're talking about pregnancy and that, so I, you know, if it was like 'well something could be wrong with your child' and then if what's wrong with you child is 'they've got type 1 diabetes' it'd be like, that's okay

F: yeah of course

B: so like the baby is perfect and you know, if she gets Type 1 diabetes and and that's the worst thing that ever happens to her

F: that's okay

B: that's absolutely fine by me but I do obsess about it and I do get concerned if I think she's drinking a lot and the reason I obsess about it is because she's my daughter and it would be my fault, you know, that's just the way I look at it

As previously explained, the communication of worry is dictated by its relevance. Here, Ben reasons that worrying about his daughter developing diabetes is pointless



because ultimately, there is only a percentage chance that she will get the disease. He limits worry further by reasoning that it is not the worst disease which she could potentially develop. However these efforts to manage his worry do not quell his attentiveness to spotting the symptoms of diabetes, nor do they serve to limit his feeling of guilt should his daughter develop the disease. It would appear from their account, that Ben's concerns about his daughter and diabetes are completely internalized; he manages the burden of worry and feelings of responsibility alone. Just as he maintains personal responsibility for the management of diabetes, and resists relying on Fiona, so too he keeps worries related to diabetes away from his wife's knowledge.

Participation in the study facilitated revelations for other couples also. In the following extracts, Clare, like her husband Jack, has had Type 1 diabetes for in excess of forty years. She has had complications with her eyes and no longer has feeling in the ends of her toes. Despite her medical condition, she is forced into the role of carer for her husband (as discussed earlier).

*Jack and Clare (lines: 757-766)*

C: I do worry that he relies too much on me when I'm diabetic as well, I think

**I: really**

C: yeah, to a certain extent

**I: do you ever forget that Clare is diabetic?**

J: yeah

**I: really**

J: yeah, yeah I do

C: how dare you ((laughs)) I shall remind you everyday

J: ((laughs))

Both Jack and Clare are equal in terms of their diagnoses (both have Type 1 diabetes and both have experienced, to varying degrees, diabetes-related complications). However this equality does not follow through into the rest of their lives as Jack is heavily reliant on Clare in terms of his care. It would seem that Jack privileges the identity of Clare as a 'carer' over that of a 'diabetic'. While Jack's admission that he

forgets that Clare also has diabetes is laughed about by both he and Clare, the significance of this revelation to her becomes apparent at the end of the interview. When I felt that we had discussed all topics outlined in the interview-schedule, I asked both participants how they found the experience of taking part in the research, to which Clare replied (directed to Jack):

*Jack and Clare (lines: 855-859)*

C: I suppose I I was quite surprised but quite pleased when you said that you forget that I'm diabetic because I do feel that sometimes but, I didn't know

J: you never asked me ((laughs))

C: well, there you go yeah

Silently feeling that her diabetes was forgotten in their relationship, Clare assumed the added burden of her husband's care. A lack of communication between Jack and Clare meant that her feelings of inequality were never voiced and thus the inequality in their relationship was perpetuated. This may also have contributed to her feelings of resentment towards her husband, which she referred to earlier.

Just as Jack and Clare's shared beliefs about Clare's status as a diabetic did not come to light until participation in the interview, similarly Glenn and Deirdre's common concerns about the future were not made apparent to each other until the following discussion took place:

*Glenn and Deirdre (lines: 378-415)*

**I: and Glenn would you talk to Deirdre much about how you feel about diabetes?**

G: No,

**I: no?**

G: no it's a man thing isn't it

D: certainly more so an Irish man, they don't talk about anything like that

G: no, there's no real, you see the thing is I'm like you in many respects, I just rely on the advances in medical science to know that

everything is going to be alright ((laughs)) in the vain hope it's okay ((laughs)) and I won't need amputations or anything

**I: yeah**

G: but I don't, I sometimes think about how this house is laid out [and]

D:

[I do!] how would I get a wheelchair up there ((laughs))

G: ((laughs))

D: I think about that, see we've never talked about that but I think of that and I'm thinking 'well the walls will be strong enough to get a stair-lift that'll be okay that bit'

G: get a chair-lift

**[lines omitted]**

D: I mean I'm thinking about that, but no I never thought you were thinking about that too

G: Mm

D: that'll tell you that obviously we don't talk about it ((laughs))

**I: yeah ((laughs))**

G: but great minds as they say

**I: yeah and Deirdre you seem to be thinking of it from a practical perspective?**

D: yes

**I: yeah, what about you Glenn? Do you look at it from the same perspective?**

G: some days when I'm feeling a bit glum about it I wonder if either of the two girls would be prepared to push me around in a wheelchair if, if Deirdre wasn't around or if she left me cos she couldn't put up with it or anything, not that that would ever happen you know what I mean

**I: yeah**

G: you just have these stupid thoughts I mean, and things come out and wonder what if I got to seventy and had an amputation or something, and it's things like that you know, but I don't dwell on it you know

**I: yeah**

G: the motto I have is it'll be alright, it'll be alright you know? It's it's, I just have these thoughts every now and again cos you know there's always the potential

Glenn's account suggests that despite attempts to manage worry by placing trust in medical developments, concerns about one's future do occasionally make an intrusion on the present. Both Glenn and Deirdre blame gender, and more specifically being 'an Irish man', for the failure to communicate these concerns. However, Deirdre also failed to communicate her concerns about the accessibility of their home to Glenn but no explanation for this is given. Perhaps being a man is a convenient excuse for not sharing feelings. What is evident here, is that both Glenn and Deirdre were separately preoccupied by a similar concern; the potential of amputation. However the underpinnings of their concerns differed with Deirdre focussing on the practical accessibility of their home and Glenn worried about the prospect of being abandoned by his wife in the event of disability and having to rely on his daughters for care. A lack of communication between partners served to silence these concerns. Amidst this silence, each partner battled with their own concerns in isolation, ignorant to the fact that their partner was doing the same. The previous chapter demonstrated that men living with diabetes do experience negative emotions and use an online support forum to 'vent' these emotions. Here, Glenn hints at the occasional presence of such emotions by stating that he sometimes feels 'glum'. He tries to limit the significance of these emotions by referring to them as 'stupid thoughts' that only occur 'now and again', however as the potential for diabetes-related complications is ever present so too is the potential to experience these feelings.

While the revelations made in these interviews may suggest the need for greater communication between couples affected by diabetes, it is not necessarily a need that is shared by partners. For Ben and Fiona (below) the revelations made during participation in the interview resulted in Fiona's desire to increase their communication about diabetes, to which Ben reluctantly agreed.

*Ben and Fiona (lines: 531-551)*

**I: would you like to talk about it more?**

F: yeah I would actually, I mean now that I'm talking about it now I'm quite enjoying it and eh, yeah I think maybe Ben's feeling a bit like 'oh I couldn't be bothered talking about it' or 'Fiona doesn't have an interest', but I would like to talk about it more because to be quite honest I probably still don't really know as much as I should know about it, do you know what I mean. Like I'm sure you could teach me a lot more about it you know, I mean I don't think that we need to start talking about it everyday because we don't need to add that pressure or burden, or invent a stress about it that maybe isn't there em, but yeah I would like to be more included in what's going on, or how he's feeling or thoughts that he might have about the baby having it or, so that could be something to work on

**I: and how do you feel about that?**

B: yeah I mean, we're talking you know ((laughs))

F: ((laughs)) you know guys and talking

B: yeah if if, if that's going to be more inclusive like the times going to come where we're going to have to teach our daughter about it

F: yeah

B: and the more you both know about it the better you know

F: yeah well I mean, yeah but not just for that, for me as well just to have a proper, a good knowledge of it and you know maybe I'm responsible for that as well, I should have done the research and stuff but, well sometimes I find anything that I read about I kind of forget you know, the ins and outs of it.

Again, the normative construction that 'men don't talk' is used by Fiona to explain Ben's seeming resistance to engage in dialogue about diabetes. When Ben does warm to the notion of talking about diabetes, there appears to be a distinction between his and Fiona's view of the purpose of such dialogue. For Fiona, increased conversation may help, not only to improve her understanding of the disease, but to understand Ben's feelings and concerns which, until participation in the study, she was unaware of. This understanding will benefit her personally, as she will feel more included as a

result. By contrast, Ben primarily focuses on the functional benefit of increased conversation. He can bring himself to agree to engage in more conversation because it may be beneficial when they teach their daughter about the disease. It would appear that to me, that Ben has an insular relationship with diabetes. He limits Fiona's involvement in the management of the disease, he does not share his worries about diabetes with her, and he focuses on the potential benefits to him of talking about diabetes, forcing Fiona to stress the importance of such dialogue to her: '*yeah but not just for that, for me as well*'.

Whether increased conversation, and the voicing of worries, will promote understanding between diabetic and partner, or improve their experience of life with diabetes, is uncertain. Indeed it may be the case for some couples that there is little to be gained by such communication, as demonstrated by Aiden and Caroline:

*Aiden and Caroline (lines: 322-350)*

C: I think it's very hard to live with someone with diabetes

**I: do you think that Aiden knows how hard it is for you?**

C: no, I can answer that one very quick, no, he doesn't, he doesn't care, sorry Aiden

**I: what do you think about that Aiden?**

A: yeah

C: ((laughs)) he has to agree

A: I have to agree

C: Aiden don't, there's one thing about him he doesn't say anything that's not, I do say to him 'if I die would you get married again' and he'll never say no and if he said it to me I'd say 'no not at all', but I may not mean it but that's a fact

A: or I'd say 'who'd have me, an old seventy year old'

[lines ommitted]

**I: do you think that Caroline knows what it's like for you living with diabetes?**

A: I think she must do now yeah

**I: do you think that she understands your perspective on it?**

A: ((pauses)) well she thinks I keep it too low and I suppose she

has her ideas and I have mine, she doesn't really know exactly how I feel

C: I get told 'well it's my diabetes, I know what I'm doing'

A: yeah like at the hospital she {diabetes-nurse} may say 'you're keeping that far too low' and she suggest I put the insulin lower and I said to hell with it, I'm going to keep to my own idea.

Aiden and Caroline's account demonstrates the potential conflicts arrived at in negotiating a *shared* life with diabetes. Caroline makes no secret of her incessant worrying regarding Aiden's welfare. Yet, voicing such concerns has not diminished her worry in any way, nor has it brought about a change in Aiden's approach to diabetes. By his own admission, he does not know how hard her life is, nor does he care. But this lack of understanding goes both ways, as Aiden believes Caroline does not understand his feelings about diabetes. As someone with diabetes, I was able to appreciate Aiden's perspective. Aiden's 'own idea' about diabetes-management is driven by a determination to prevent complications, in order to sustain the lifestyle he enjoys. He keeps his sugar-levels as low as practically possible in order to prevent the damage associated with high sugar-levels. At the age of seventy-one, having lived with Type 1 diabetes for forty-six years, Aiden has no diabetes-related complications. If the success of diabetes-management were to be measured in physical terms, Aiden's approach has worked. The downside of Aiden's approach is that it does not attend to the impact, or existence, of diabetes outside the confines of the individual diabetic. While he may be physically fit, his wife is incessantly worried. The independence he has achieved from diabetes has been at the expense of Caroline's. Because he is entrenched in a belief that diabetes is *his* disease, Caroline's attempts to change his approach, through communicating her concerns and worries, are futile.

## 6.2 Discussion

This study set out to gain an understanding of the familial experience of living with Type 1 diabetes, as informed by a group of men with Type 1 diabetes and their partners. Perhaps most significantly, the findings illustrate the way both men affected by diabetes and their partners, preserve the normality of their lives by

dividing diabetes into two distinct spheres. Publicly, therefore, diabetes is a disease which affects day-to-day living. It is a *manageable* disease, and management styles are negotiated by the couple through varying levels of reliance. Beyond the day-to-day concerns of diabetes, and invisible to partners and the public, diabetes is a disease which places a psychological burden on those affected by it. This burden is rarely spoken of and is managed independently by the sufferer.

As detailed in the previous empirical chapters of this thesis, research involving men with diabetes is generally lacking and the research which does exist is dominated by studies examining diabetes-related erectile-dysfunction (e.g. Bacon et al. 2002; Corona et al. 2004; & De Berardis et al. 2002). While a body of research involving both male and female diabetics and their partners does exist (as discussed at the outset of this chapter), the current study represents one of the few that looks at the broader experience of living with Type 1 diabetes as informed by *male* diabetics and their partners.

As mentioned, the separation of diabetes into the 'overt' sphere and the 'covert' sphere could be viewed as an attempt to preserve the *normality* of their lives. The 'overt' diabetes is a treatable, non-life-threatening, physical condition. By routinely attending to its day-to-day management, *normal* life can be maintained. Couples negotiate diabetes-management styles in relation to the levels of reliance they place upon one another. Under the management style of 'resisting reliance', the male partner maintained responsibility for the management of his disease and asserted this by minimising his partner's participation in his care. Men who resist placing too great reliance on their partners may be protecting their independence and their status as a 'normal' healthy male as opposed to adopting a sick-role. Additionally, by maintaining responsibility for the management of the disease and the organisation of diabetes equipment, men are able to protect against interruptions to normal activities which may occur if their non-diabetic partner failed to pack everything. This management style compliments the findings of other research which has looked at couples living with diabetes. For example, Trief et al. (2003) noted occasions where spouses' desire to participate in the management of diabetes was blocked 'by a partner who refused to share his or her burden' (p. 63). The reasons the authors note for this can be likened to reasons why Ben (Extract 2 above) opted to take full



responsibility for the organisation of his diabetes equipment, as he lacked trust in his partner's ability to effectively carry out this task. Indeed this management style is marked by seeming disparity between the male diabetic and his partner in their understanding of her role in the management of his disease. The analysis demonstrated attempts by male partners to limit the role accredited to their spouses, while occasionally contesting female partners' accounts of their involvement. Gregory (2005) noted, in the context of families affected by chronic illness that 'many acts of 'caring about' are taken for granted in the busy everyday run-of-the-mill business of getting on with life' (p. 375). Thus the reduction, for example, of Deirdre's role to 'food-preparation' is not necessarily unusual. Previous research, though dated, has suggested that such disagreement regarding spousal roles, in the context of diabetes management, can have a negative effect on marital satisfaction, while also suggesting that patient satisfaction with diabetic life was higher when spousal involvement was lower. (Peyrot, et al. 1988).

While it may be the case that some men with diabetes prefer to resist relying on their partners and thus maintain control of the management of their diabetes, this study has demonstrated that for others, the involvement of the female partner is beneficial. In contrast to *resisting reliance*, the management style of *sharing 'self'-management* is underpinned by an appreciation that it is not possible to restrict the parameters of diabetes and ultimately it is too great for one person to deal with alone. By sharing diabetes with their partners, men benefited from a comprehensive system of care. By approaching diabetes-management as a team and bringing to it a comprehensive skill-set, these couples can enjoy a lifestyle in which they plan for diabetes rather than be interrupted by it. While sharing the management of diabetes, partners also made a deliberate effort to protect the normality of their lives. Women empowered their partners and encouraged them to become more attuned to the demands of their disease, thereby containing the level of reliance placed upon them. This in turn had the effect of protecting their normal identity as wife/partner from becoming that of 'carer'. Underpinning this management style is a mutual understanding of diabetes as a serious disease. While this was not specifically articulated by the participants, men's recognition that they would benefit from the assistance of their partners, and their partners' preparedness to do so, would suggest a shared-belief that the effort to manage diabetes successfully is too great for one person to achieve.

By contrast, when the illness-beliefs of 'patient' and partner diverge, spouses tend to maximise, or minimise, their expression of illness-beliefs in order to achieve balance (Heijmans, de Ridder & Bensing, 1999). Citing, Thompson and Pitts (1992), Heijmans et al. (1999) explained this as: 'when patients minimize their illness, spouses tend to maximize and become overprotective and vice versa (Thompson & Pitts, 1992). In the case of the management style of *picking up the pieces*, such divergent views were apparent. The minimal attention Aiden gave to the day-to-day management of his diabetes was balanced by his wife's constant care. Jack's minimisation of his role in the onset of diabetes-related complications was balanced by Clare's assertion that he brought it on himself, while his, seeming, lack of attention to diabetes in the past is balanced by his wife's duty of care in the present. As with the other management strategies, the management style of 'picking up the pieces' also served to protect normality. Here, normality was achieved for the male partner only. He prioritised the normal functioning of his lifestyle, adopted a management regimen which complimented this pursuit of lifestyle, and relied on his female partner to deal with the consequences of this pursuit. In these cases, the partner's experience of illness could be likened to what Öhman and Söderberg (2004) referred to as 'a shrinking life' which they further explain as including: a 'reduced sense of personal freedom and an increased sense of responsibility for the care of the ill person' (p. 405).

As the literature into the self-management of diabetes has illustrated, there are numerous factors which influence how diabetes is managed, including ethnicity (e.g. Hjelm, Nyberg, Isacson, & Apelqvist, 1999), gender (e.g. Broom & Lenagh-Maguire, 2010) and access to healthcare (e.g. Jack et al., 2010). In the case of couples affected by diabetes, the dynamics of the couple's relationship may act as an additional factor which informs management strategies. In their quantitative research of marital quality and adherence to the diabetes regimen (mixed gender), Trief, Ploutz-Snyder, Britton, and Weinstock (2004) demonstrated moderate support for their hypothesis that a better marital relationship is a predictor of adherence to the diabetes regimen. While in their study of the use of positive and negative social control by spouses of diabetics (mixed gender), Stephens et al. (2010) found that spouses who used positive social control strategies (such as encouragement), their

partners responded with 'health-enhancing behaviour'. While negative control strategies, such as warning, nagging and inducing guilt, had the opposite effect to that intended, and resulted in poorer dietary adherence. Thus, if partners are to become a part of diabetes-management, in a way which is mutually beneficial, 'appropriate interpersonal techniques' may need to be established (Peyrot et al., 1988).

It is also important to note, that these management styles are not fixed. Participants in the research alluded to changes in their approach to management. For example, Aiden (who was seventy-one years of age at the time of the interview) had recently participated in a DAFNE programme and he told me that this course equipped him with the skills to take better control of his diabetes. His wife Caroline agreed and advised me that '*DAFNE saved her life*'. Similarly, we saw in this study Brian's account of how he has learned to take greater control. He too had recently participated in a DAFNE programme and was enjoying the benefits of this approach to disease-management. This is particularly interesting given his view of the DAFNE course which he offered when I first met him on a one-to-one basis (see Chapter IV). Previously he described the restrictive and mundane nature of the DAFNE approach. His change in attitude came since the birth of his first child, which brought with it a new desire to be healthier in order to fulfil his duties as a father. As a result he enrolled in the DAFNE programme and since his participation in both studies, he has informed me that he has moved on to insulin-pump therapy. This highlights the need to attend to life-stages and transitions in adulthood. As Anderson (2006) concluded: 'Clearly, life stage transitions must be accounted for by investigators as the person with a chronic illness and his or her family members move through the adult years' (p. 333).

While the practical management of diabetes is carried out openly by the couple, the psychological burden of the disease is dealt with *covertly* on an individual rather than familial level. This is similar to the ways in which Charmaz (1994) asserted men deal with uncertainty. In her explanation of this, Charmaz used Husserl's (1970) reference to 'bracketing': 'Bracketing means setting apart this event by putting a frame around it and treating it as something separate and removed from the flow of life. The impact of the event upon identity lessens when this event is separated from

social and personal identity' (p. 274). Perhaps the isolation of emotional burden in this way also serves to protect the normality of everyday life. By attending to the management of the disease, and denying its emotional fall-out, a well-managed diabetic and his family can enjoy a life very similar to that of non-diabetics.

Men's efforts to keep their concerns regarding diabetes hidden could be viewed as an attempt to protect their masculine identity, as the 'doing of emotion' is traditionally associated with femininity. Indeed the functionality of worry, referred to by many of the men, may also be a way of legitimising expressions of worry. In the case of the men in this study, worry served as means of focussing their attention on the management of their disease. In contrast to the male participants who saw a benefit to worry, female participants often spoke about avoiding triggers of worry (e.g. discussions or information about complications). This is also consistent with research into gender differences in worry (Robichaud, Dugas & Conway, 2003), in which women tend to engage in more thought suppression (or cognitive avoidance) than men.

The containment of worries and concerns to the 'covert' sphere of diabetes may also be likened to 'protective buffering', which is: 'a matter of hiding concerns, denying worries, and yielding to the partner to avoid disagreements' (Coyne & Smith, 1991, p. 405). This strategy has been identified by a number of researchers as a coping style of couples experiencing, amongst others, prostate cancer (Boehmer & Clark, 2001), myocardial infarction (Coyne & Smith, 1991), and HIV infection (VanDevanter, Thacker, Bass & Arnold, 1999). In their study of marital adjustment to diabetes, Peyrot, McMurray and Hedges (1988) noted that many of their participants commented that they never talked about diabetes. The authors suggested that this 'secrecy' may be maladaptive in terms of marital adjustment to diabetes, but at the same time may be a positive aspect of adjustment for the individual with diabetes. More recently, in their study of spousal support to patients with asthma or diabetes, De Ridder, Schreurs and Kuijer (2005) observed a gender interaction in relation to protective buffering. They observed that 'female patients experience worse physical health when their husbands hide their concerns whereas male patients, in contrast, benefit when their wives do not discuss their worries with them' (p. 506). The benefit of protective buffering, they cite, is that it may enhance the

'patient's' sense of control over his or her illness.

In addition to the gendered differences in worry, explicit references to normative gender behaviours were made by many of the women in the interviews, with specific reference to their partners' reluctance to *talk* about diabetes. Gender was also made implicitly relevant. For example, men's attempts to maintain personal control over their diabetes, and their reluctance to share responsibility for the management of the disease with their partners, is synonymous with the traditionally masculine desire for autonomy. Women's displays of health-supervision, and the occasional positioning of their partners as child-like could also be viewed as complying with hegemonic masculinity (Seymour-Smith & Wetherell, 2006).

The separation of the two spheres of diabetic-life is perpetuated by a lack of communication between partners regarding the emotional burden associated with diabetes. As evidenced in the analysis, many couples were not aware until participation in the interview, that their partners shared their feelings about diabetes. These *revelations* appeared to benefit female partners, as interpreted by Fiona's desire to engage in such dialogue with Ben on regular occasion, and Clare's expression of happiness that her silent feelings of being taken-for-granted had been vindicated by Jack's account. Indeed, there was a visible transformation in Clare's demeanour from the beginning of the interview to the end, which I can only describe as an apparent sense of relief, perhaps borne out of the articulation of her resentment towards her situation. Given these observations, it would be easy to encourage greater communication between couples. However, as the previous research in this area (already discussed) has highlighted, such communication may not necessarily benefit both partners (e.g. De Ridder et al., 2005). I would suggest, however, that the qualitative interview serves not only as a means of data-collection, but it may have beneficial effects for those who participate in it.

### **6.3 Summary**

This chapter offered a theory of how men with Type 1 diabetes and their partners, achieve a *normal* life in the presence of disease. This is accomplished by separating diabetes into two spheres: the 'overt' and the 'covert'. Within the realms of the 'overt'

sphere men and their partners negotiate the day-to-day management of diabetes through varying levels of reliance. The strategies of each approach to management serve to achieve as normal a life as possible, by containing the interruption of diabetes. The segregation of worries and concerns to the 'covert' sphere of diabetes, further protects against the interruption of diabetes, whilst also protecting masculine identity.

## **Ch. VII Discussion**

### **7.0 Introduction**

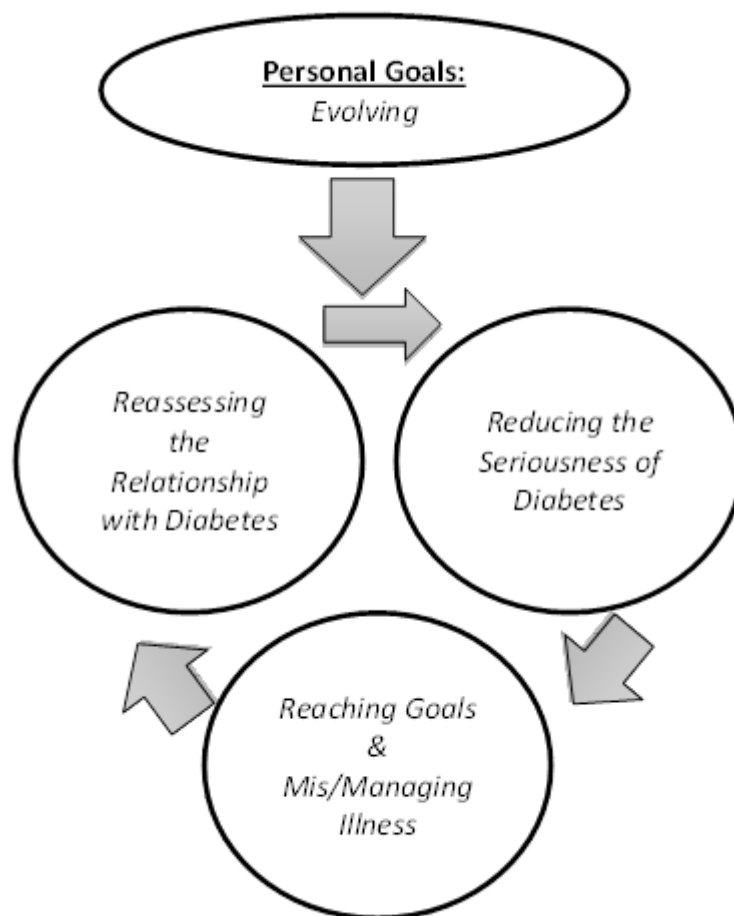
The aim of this study was to gain an understanding of men's *holistic* experience of living with Type 1 diabetes. This topic was explored from the perspective of men with the disease, and from that of their partners. An examination of the use of an online-forum, specifically dedicated to men with diabetes, also facilitated the exploration of the topic. In the opening chapter of the thesis, I provided a background to the research and my personal motivation for engaging in this subject-area. The second chapter reviewed the literature relevant to the research. A need for qualitative research into men's experience of Type 1 diabetes was identified. The third chapter detailed the methodology chosen to explore this topic. I provided specific details of the grounded theory approach I used and I explained the rationale for choosing this method of analysis. Chapters four, five, and six detailed the empirical research undertaken as part of this PhD. The findings were presented in relation to the existing research in these areas. In this seventh and final chapter, I review the main findings of these studies. In section 7.2 I discuss the main points highlighted by the research as a whole and consider their contribution to the literature. In section 7.3 I consider the quality of the research in response to Charmaz' (2006) criteria for assessing the quality of grounded theory research. Sections 7.4 and 7.5 discuss the implications and limitations of the research, respectively, before directions for further research are pointed to in section 7.6. In section 7.7, I reflect on the research process and offer a brief conclusion.

### **7.1 Review of Main Findings**

The empirical research detailed in Chapter IV offered a theory of adjustment to life with Type 1 diabetes based on the experience of 15 men with the disease. Following a grounded theory analysis of interviews with these men, I argue that the ultimate goal of adjustment is to achieve personal goals by controlling the influence of diabetes on one's life. The ever-evolving relationship between diabetic and diabetes was highlighted as personal goals shift in response to changing life events and

personal circumstances. The reassessment of one's relationship with diabetes is necessitated in response to these changes, which in turn informs how men manage their diabetes. I also noted that the extent to which gender influences health-related behaviours varied between men in the study. The fluid and malleable nature of adjustment reflects the chronicity of the disease. The findings of this study are depicted in Fig. 1 (below).

*Fig. 1 Men's Adjustment to life with Type 1 diabetes (Chapter IV)*

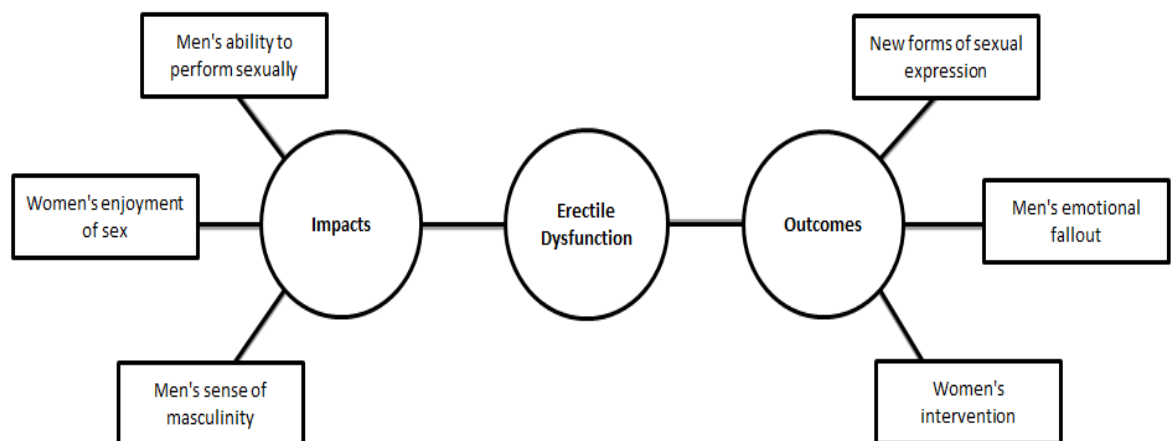


Chapter V detailed the findings of a grounded theory analysis of postings to the 'Men's Corner' of an online diabetes forum. A conceptual map of the findings is presented in Fig. 2 (below). The analysis centred around the experience of erectile dysfunction, and highlighted that, rather than being 'a man's problem', the couple were central to the experience of this condition. It has demonstrated that ED is not only an ailment which inhibits men's ability to perform sexually, rather it serves to



separate them from the successful demonstration of their sexuality; for some, it limits their partners sexual satisfaction and in these cases forces their partners to assume an active role in their diabetes-care; it requires men and women to find new forms of sexual expression; and finally it causes significant emotional turmoil for the men who are unsuccessful in their quest to eradicate ED. In this chapter, I also attended to men's use of the online forum as an environment in which they could 'vent' their feelings of emotional despair, caused by living with ED. The extreme expression of emotion by men on this forum, challenges traditionally masculine views of men as being unwilling to express emotion. I discussed the possible reasons why men engaged in such emotive accounts online, and the implications their expressions had for their masculine identity.

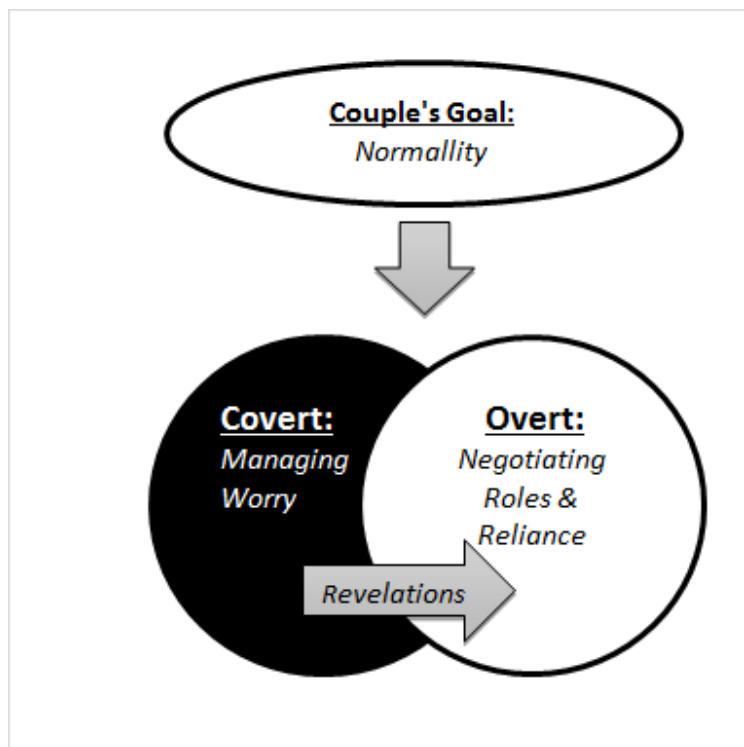
*Fig. 2 Sharing ED (Chapter V)*



Chapter VI dealt with the familial experience of living with Type 1 diabetes. Following interviews with ten couples (in which the male partner had Type 1 diabetes), the analysis illustrated how these couples achieve normality in their lives by separating diabetes into two distinct spheres: the 'overt' sphere and the 'covert' sphere (see Fig. 3 below). Within the 'overt' sphere, men and their partners negotiate the day-to-day management of diabetes through varying levels of reliance. Men who resist placing too great a reliance on their partners may be protecting their independence and their status as a 'normal' healthy male as opposed to adopting a sick-role. For other couples, normality is achieved by sharing the management of

diabetes. In these cases, normal life is protected by jointly planning for diabetes, rather than being interrupted by it. Additionally, the partners in these couples protect their normal status of wife or partner from becoming that of carer. The management style of 'picking up the pieces' illustrates how men achieve their goal of a normal life by passing the responsibility for the management of diabetes to their partners. In these cases, normality is achieved for the male diabetic only. The segregation of worries and concerns to the 'covert' sphere of diabetes, further protects against the interruption of diabetes, whilst also protecting masculine identity.

*Fig. 3 Couple's Adjustment to life with diabetes (Chapter VI)*



## 7.2 Discussion of Main Findings

Overall, the findings of this study point to three significant areas that require discussion. The first of these is the notion of diabetes as an *all-encompassing* disease. The second considers the *evolving* nature of diabetic-life, and the third

concerns the significance of *gender* to the experience of diabetes.

### *7.2.1 Type 1 diabetes as an all-encompassing disease*

Throughout the studies, men consistently made efforts to contain the presence of Type 1 diabetes and achieve a 'normal' life. They endeavoured to achieve this by minimising the seriousness of the disease, by prioritising the pursuit of their personal goals over adherence to the recommended diabetes regimen, by separating themselves from the causation of diabetes-related complications, and by isolating and silencing, the psychological burden of the disease. Paradoxically, these varied attempts to minimise, collectively illustrate the all-encompassing nature of diabetes. Progressing from its rootedness in a disordered pancreas, diabetes negates 'normal life', it challenges men's beliefs about personal agency, it threatens masculine identity and it burdens the mind.

The existing research into men with diabetes points to men's efforts to minimise and normalize the presence of the disease. For example, Koch et al. (2000) found that men viewed diabetes as part of life and experimented with their lifestyles in order to establish an individualized approach to diabetes care. While the findings in Chapter IV support this, when one considers these findings alongside those of chapters V and VI, a more *holistic* understanding of men's experience of life with diabetes is provided – an understanding which is not accounted for by the existing literature. Men's attempts to minimise the presence of diabetes only serve to allow temporary enjoyment of 'normal' life. While 'normal' activities are acted out, it would seem that diabetes remains present in men's minds. The preoccupation caused by diabetes, while not spoken of, is difficult to minimise. Were it not for the interviews with men and their partners, this preoccupation would not have been identified as a prominent aspect of men's experience of life with diabetes.

Diabetes also encompasses family life. It moves beyond the confines of the body to impact on men's partners. They become involved, to varying extents, in the management of diabetes and, like their male partners, are silently preoccupied by the worries of the disease. Yet little attention has been given to the experience of partners of men with diabetes in the literature. In this research, partners facilitated

the search for normality, they shared some of the responsibility of illness, yet were regularly positioned on the periphery of the illness experience. While many of the men with diabetes may express ownership of it, they are unable to confine the reach of the disease to their own experience. This was particularly apparent to men following the onset of diabetes-related erectile-dysfunction. In these instances, men became overwhelmed by a feeling of failure, resulting from their perceived inability to satisfy their partners' sexual needs.

### *7.2.2 The evolving nature of the relationship with diabetes*

The research highlighted the evolving nature of one's relationship with diabetes and experience of diabetic-life. I suggest that the potential for flux in the way one engages with diabetes is located in their personally-held goals. As these goals inform the extent to which the diabetes regimen is assimilated into everyday life, a change in goals can result in a change in the way diabetes is managed. This was exemplified in the research, by the priority men attached to the goal of 'working hard'. In order to achieve this goal, minimal attention was given to diabetes. However, when men set as their priority, the goal of 'taking care of others', their engagement with diabetes shifted so as to ensure this goal could be achieved. Similarly, for couples whose goal was to preserve the normality of their lives, the psychological weight of diabetes was denied, whilst they collaborated (to varying extents) to limit the interruption of diabetes in their lives.

These findings, which highlight the ever-changing nature of diabetic-life, build upon previous research into both Type 1 and Type 2 diabetes. For example, Paterson et al. (1999) note that 'as the personal and social context changes, people's perspectives shift in the degree to which illness is in the foreground or background of their reality' (p. 307), thus people's experience of illness, and the way they live with it, is ever-changing. The way men and their partners confront diabetes in this research can be likened to the 'science of one' stage of integration which Hernandez (1996) describes as the stage in which diabetes is integrated into life but does not dictate how life should be lived. In my research, the integration of diabetes served the purpose of goal-attainment. It was, therefore, a means to an end rather than a controlling presence throughout the lifecourse. In contrast to the existing literature, I do not view

the evolving relationship with diabetes as a consequence of developmental stages of expertise in diabetes self-management (Paterson & Thorne, 2000), nor do I view it as a process whereby the 'personal self' and 'diabetic self' gradually become integrated (Hernandez, 1996). Rather, I propose the evolving nature of one's relationship with diabetes as a *consequence* of changing life goals.

The significance of personal goals was previously highlighted by Watts et al. (2010) who noted the potential conflict between the pursuit of personal goals and the satisfaction of health-related goals, concluding that if psychological and physical quality of life is to be maximised, both sets of goals need to be attended to.

### *7.2.3 The significance of gender to the experience of diabetes*

Normative constructions of what it is to be a man, were made relevant in the research. For example, the priority men attached to 'working hard', their desire for control over their lives, their reluctance to talk about their feelings, and the importance they attached to sexual-functioning can all be viewed as consistent with the attributes associated with hegemonic masculinity. At the same time, men's desire to be healthy in order to 'take care of other people' and their renegotiation of sexual intimacy (in response to the presence of ED) indicates alternative expressions of masculinity. These findings are consistent with Robertson (2007) who suggested that masculine ideals are open to change throughout the life-course. Here, men found alternative expressions of masculinity as their personal circumstances changed. Men also found ways to legitimately engage in behaviours which otherwise could be viewed as 'feminine'. For example, in the case of men's emotional expression, it would appear that the online forum provided men with the safe environment in which to talk about their feelings. The anonymity afforded by the forum safeguarded men's masculine identity in the wake of such 'feminine' outpouring.

At the same time, one could also identify variations in the way femininity was expressed in the research. Chapter V pointed to the differences between women in the importance they attach to sex: varying from those who emphasise intimacy (through cuddles, holding hands etc.), to others who express their frustration at a lack of penetrative sex in their relationship. Additionally, with regards to the couples

interviewed in Chapter VI, women were not always positioned in the carer's role one would stereotypically equate them with. Rather, some men endeavoured to manage their diabetes independently, while other couples shared the responsibility. However, there were regular instances of women positioned in maternal-like roles which are consistent with accounts of hegemonic masculinity. While men's reluctance to talk about their feelings regarding diabetes were commonly attributed by female partners to 'being a man', women's accounts would suggest that they also do not share their concerns about diabetes with their partners.

While observations about the performance of traditional masculinity in men's accounts were made, I would not suggest that the way men engage with their health is dictated by their gender. As stated, the personal goals of the individual dictate the extent to which diabetes will be integrated into everyday life. These goals are unique to the individual with diabetes, and are influenced by their personal circumstances and biography. Indeed, it may be the case that women with Type 1 diabetes engage with diabetes in the same way. Thus, while gender was made relevant to varying extents throughout the studies, it by no means dictated the nature of men's engagement with diabetes.

#### *7.2.4 The contribution of the thesis to men's health research*

This thesis contributes to the field of men's health research by providing a rare investigation into men's accounts of living with chronic illness. As the literature considered in Chapter II, and indeed throughout this thesis, demonstrates, men's experience of life with Type 1 diabetes has largely been neglected.

A current of hegemonic thinking still informs discussions about men and health. Perhaps this is the reason so few studies have investigated men's experience of diabetes (particularly from a qualitative perspective) as there is a lingering assumption that men are either uninterested in health or are not prepared to talk about their health. The research presented in this thesis challenges this assumption. It has been demonstrated here, that men are prepared to share their accounts of illness and are also prepared to engage in emotive accounts of their experiences when given a safe environment in which to do so.

### *7.2.5 The contribution of the thesis to diabetes research*

In relation to diabetes research, this thesis makes an important contribution to the field by acknowledging and promoting the experiential knowledge of the person affected by Type 1 diabetes. Against a backdrop of biomedical and mainstream health psychology research in which the individual is reduced to that of a 'subject', the critical approach of this thesis promoted the patient to the status of collaborator in the research. Going forward, I hope that research into diabetes shall continue to step away from a reductionist focus and attend to the holistic experiences of people with diabetes.

### *7.2.6 Contribution of the thesis to grounded theory research*

This thesis builds upon a strong foundation of GT research into health. As I mentioned at the start of Chapter III, I first became interested in GT having read the work of Kathy Charmaz. As a student, I found her research accessible while as someone with a chronic illness, I identified with her writings.

One of the challenges when getting to grips with GT as a method, is the vast amount of instruction and procedures associated with its original versions. I think that the quality of the data and depth of analysis achieved in this thesis testifies to the alternative use of an abbreviated version of GT. Additionally, my use of GT in the analysis of postings to an online forum represents a novel application of the method and provides a capable alternative to the versions of content analyses which currently dominate this field of research.

## **7.3 Assessing the Quality of the Research**

In this section, I consider the elements of Charmaz' (2006) criteria for assessing the quality of grounded theory research to the present study.

### *7.3.1 Credibility*

To assess the credibility of research, Charmaz (2006) proposes a number of

questions regarding sufficiency of data, breadth of empirical observations, and provision of evidence with respect to research claims.

My approach to data collection for the studies detailed in Chapters IV and VI, involved snowball sampling and recruitment through press-releases. By using these methods of recruitment, as opposed to going through the NHS or diabetes support-groups, I was able to recruit a group of participants who varied in their involvement with health-care clinics. Some regularly attended check-ups while others did not attend at all. Additionally, the participants were either Irish or English, and thus were patients under two different health-care systems. I also recruited men from a wide-range of age-groups, in order to attend to potential variations in the experience of illness between these men. This breadth of ages also mean that some of my participants had retired, while others were still working. Some were in university, while others were married and starting families. This broad spectrum of participants enabled me to draw on a variety of experiences and allows for greater generalizability of findings. That said, my group of participants were all White Irish or White English, and observed to be heterosexual. This, unintentional, exclusion of men of other sexual orientations and men of other ethnicities serves to limit the generalizability of the findings.

In addition to data collected through interviews, data from online discussion boards were also analysed (Chapter V), allowing for an insight into the issues made relevant by men in an anonymous interaction online. The data informing this thesis has, therefore, come from multiple sources. The credibility of my conclusion that diabetes is an all-encompassing disease is enhanced, therefore, as it is based on the analysis of fifteen one-to-one interviews with men with Type 1 diabetes, ten interviews with diabetic men and their partners, and the analysis of 122 postings to an online forum.

### *7.3.2 Originality*

With regards to originality, Charmaz (2006) asks questions about the insights made in the research. Are they new? What is their significance? And how do they relate to current ideas?



This research address an important gap in the literature, that of men's experience of life with diabetes. It builds upon what we already know about men's attempts to minimise diabetes in order to enjoy a normal life, but goes beyond such research by illustrating minimisation as a strategy which facilitates *temporary* enjoyment of normality, rather than a complete escape from the disease.

This research also builds upon what we already know about the experience of living with diabetes as every-changing. Unlike the existing literature, I argue that such changes are responsive to changing personal goals (which may be linked to changes in life-stages), rather than a progressive process of integration informed by a greater understanding of diabetes.

### 7.3.3 *Resonance*

With regards to 'resonance', Charmaz (2006) asks: '[d]oes your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?'

It is impossible to argue that my research *resonates* with my participants, as I have not shared the details of my findings with them. However, as someone who shares my participants' circumstances, I can confirm that the findings resonate with *my* experience of life with diabetes. I can relate to their prioritisation of goals over the management of diabetes and I too partake in the silencing of my worries about diabetes. Indeed, I have found the parts of this thesis in which I share details of my feelings about diabetes, the most difficult to write. This resonance with my own experience does not permit me to infer that women with diabetes experience life with the disease in the same way as men. Rather, I would suggest that regardless of gender, living with diabetes holds common challenges for, and results in similar strategies of adjustment in both men and women with the disease.

### 7.3.4 *Usefulness*

In assessing the usefulness of research, Charmaz (2006) asks: 'how does your work

contribute to knowledge? How does it contribute to making a better world?'

This research contributes to knowledge, in that it offers an understanding of men's *holistic* experience of living with diabetes – an experience which has previously been under-researched. Based on the findings, and as will be discussed in the following section, the research makes important recommendations regarding the provision of care to people affected by diabetes. Most importantly, this research provides an understanding of diabetes as a disease which not only places a physical toll on the 'sufferer', but results in an incessant psychological burden for the diabetic and their partners.

It would be bold of me to claim that my research will contribute to a better world. But, if it can contribute to a greater understanding of what life is like for people affected by diabetes, I feel that this may go some way to bettering the lives of these people. A more widespread understanding of diabetes as a disease which exerts a psychological burden, as well as a physical toll, may permit those affected by it to open up about their burden and share some of the strain.

#### **7.4 Implications of the Research**

The centrality of individuals' goals to their experience of diabetes highlights the very personal nature of diabetic-life. If one is to establish a 'fit' for diabetes in their lives which varies at different times depending on their personal goals, how can universal recommendations for the management of diabetes be successful? I would suggest that health-professionals need to equip people with diabetes, with the skills necessary to allow for variation in their daily lives, without resulting in deviation from the management of diabetes. Education about the interaction between insulin and carbohydrates (for example the DAFNE course) is one way of achieving this. Another, is through advanced treatment options, for example insulin-pump therapy, which eliminates the restriction of meal-times from one's day, whilst also reducing the frequency of hypoglycaemia. Essentially, diabetics must be given the skills necessary to prescribe their own treatment regimen, which will fit around their lives and aid the pursuit of their personal goals.

The findings also highlight the centrality of the couple to the experience of life with diabetes. In order for partners to feel involved in the management of a disease which undoubtedly affects them, efforts should be made to involve partners in aspects of the management of the disease. This will not only serve to enhance their sense of inclusion, but will lighten the burden of disease on the individual with diabetes. This inclusion of partners is particularly important in the context of treatment of erectile-dysfunction. The findings here highlight the need for a system of care which not only prescribes chemical treatments to restore erections, but does so alongside attending to the psychological well-being of those affected by ED in a manner which is inclusive of the couple.

While men and their partners shared, to varying extent, the physical management of diabetes, each suffered silently under the psychological burden of the disease. This aspect of diabetic-life must be addressed if the quality of life of those affected by diabetes is to be maximised. Men's preparedness to 'vent' their emotions in an online forum would suggest that this is a safe environment in which men can talk about their feelings without experiencing a threat to their masculine identity. Thus, healthcare providers should examine ways of encouraging men with diabetes to join such forums, whilst also pointing their partners to similar avenues of discussion.

I would suggest that by implementing these recommendations, not only will the quality of life for those affected by diabetes improve, but the cost of the treatment of diabetes to the health-service should also decrease. As the pursuit of personal goals informs the extent to which the management of diabetes is assimilated into daily life, when adherence to the regimen and the attainment of goals appear mutually exclusive, the regimen will be abandoned. Thus, by providing treatments and education to allow for the attainment of both, physical health shall be preserved alongside psychological well-being.

## **7.5 Limitations of the Research**

A failure to attend to the experience of gay men or same-sex couples affected by diabetes, is a major limitation of this research. Greater planning in the recruitment process may have helped to accommodate these groups. As it stands, I do not claim

to generalise the findings of this research to all men with diabetes, as the research has not attended to the experiences of homosexual men.

As this research focused solely on men with Type 1 diabetes, I cannot argue that the observations made here are unique to men. Comparable research must be carried out with women if likeness or uniqueness is to be demonstrated. Similarly, the experiences of men affected by Type 2 diabetes have been neglected.

My decision not to engage in *theoretical sampling* limits the extent to which I can claim this research to represent Grounded Theory. Whilst I feel the depth of data obtained from the interviews, and the online forum, provided extensive opportunity to evidence and test the developing analysis, the use of theoretical sampling would have provided me, at this stage, with greater support to my claims of producing a grounded theory.

## **7.6 Directions for Future Research**

Having focused on the experience of men with Type 1 diabetes, future research could also examine if a similar path to adjustment is pursued amongst men with Type 2 diabetes and men with other chronic illnesses. The quality of the data obtained from my participants meant that many areas of interest were highlighted but could not be explored here. It is suggested that future research look at such areas as adjustment to diabetes in specific age-groups; how varying types of work impact upon the management of chronic illness; and how personally-held definitions of diabetes compare with healthcare professionals' definitions, and how the relationship between patient and doctor is affected (if at all) by these definitions.

This research provided a brief, and novel, insight into how men and women are affected by diabetes-related erectile-dysfunction. While some efforts have been made to do the couple's experience of ED in the area of prostate-cancer research (e.g. Boehmer and Clark, 2001) research into couples affected by diabetes-related erectile-dysfunction is still lacking. Further in-depth qualitative investigation is required into the issues raised here.

## **7.7 Reflections: The Research Process**

While attending my six-monthly consultation with my diabetes specialist in 2008, I informed him of my upcoming PhD research. He asked if I thought it was a good idea to research diabetes while also living with the disease. I replied, that as my research focused on men with Type 1 diabetes, I did not expect it to be problematic for me. Inherent in my response was the assumption that somehow my gender would serve to distance me from my participants' accounts. Reflecting on this encounter now, I appreciate the naivety of my response. Whilst I thoroughly enjoyed meeting with each of my participants, and having the rare opportunity to listen to their experiences, there were times I found myself consumed by diabetes. On these occasions, both my health and the progress of my research suffered.

Nonetheless, conducting the research, and in particular the data collection, was a very enjoyable process. I found myself in the privileged position of being able to give my participants' the opportunity to talk about their experiences – an opportunity they had not received from healthcare professionals during the duration of their illness. I hope that I successfully conveyed their voices and relayed their experiences in the final thesis.

Having reached the conclusion of this research, I would not say that my feelings towards diabetes have changed. My fear of developing diabetes-related complications in the future remains very much present in my mind, though rarely articulated. As my friend's start to have families, I start to think more and more about the dangers of diabetes during pregnancy and the risks of passing on diabetes to my children. I do appreciate, however, how fortunate I am, in comparison to my participants, to benefit from modern and sophisticated treatment in the form of insulin-pump therapy. My wish is that my participants, and indeed everyone who is affected by Type 1 diabetes, should have the same standard of care as I have been granted.

Getting to grips with the grounded theory methodology was, at first, quite a challenge. I found the breadth of procedures, and variations between theorists, made it rather difficult to establish an approach which served to satisfy all of the principles

of grounded theory. Ultimately, I followed the advice of the originators of this method, Glaser and Strauss (1967), who advised: 'grounded theory may take different forms' (p. 31). Indeed, this decision to do so enabled me to interact more intuitively with the transcripts rather than feeling restricted by procedures. Whilst at times I struggled to progress from basic description to levels of abstract analysis, I found that *free-writing* and perseverance helped me to make the linkages from codes to concepts to categories.

## **7.8 Concluding Comments**

Based on the findings of three empirical studies, this research provides an understanding of the *holistic* experience of living with Type 1 diabetes, as informed by a group of men with disease, across different settings. The one-to-one study with diabetic men, gave an insight into how a relationship with diabetes is established, in response to the perceived congruency between the management of diabetes and the attainment of personal goals. This relationship is not fixed, rather as personal goals shift (in response to changing personal circumstances) so too does men's relationship with diabetes. The study of postings to an online forum, illustrated the ways men and women come to grips with the presence of diabetes-related erectile dysfunction in their lives. I explained how the incongruency between 'patients' and partners' accounts of causation force partners into an interventionist role with regards to the management of diabetes. Importantly, this study also illustrated the threat to masculine identity from the presence of ED, and the subsequent emotional fall-out of men's perceived inability to satisfy their partner's sexual needs. The final empirical study provided a valuable insight into how, both men and their partners, strive for a 'normal' life through the containment of diabetes. In this case, diabetes is managed as two distinct diseases: one which impacts on practical day-to-day activities (overt sphere) and the other which impacts the psychological well-being of both men and their partners (covert sphere). The lack of communication between men and their partners serves to perpetuate the separateness of these two spheres, and thus prolong the solitary burden of this aspect of the disease.

On consideration of these findings collectively, I suggest that diabetes is an all-encompassing disease. While men, and their partners, may be able to minimise the

seriousness of it and pursue 'normal' life-goals, its potential to interrupt 'normality' is ever-present. Indeed, I would suggest that it is the psychological burden of living with diabetes which negates normality. It is important therefore, for this aspect of diabetic-life to be acknowledged and attended to if the quality of life of those affected by diabetes is to be maximised.

The findings support previous research which illustrate the ever-evolving nature of adjustment to life with diabetes. While previous research would suggest that changes are borne out of a greater understanding and acceptance of the disease, I would suggest that changes are reactive. They represent a response to the evolving goals of the individual with diabetes. With each new goal, re-engagement with diabetes is necessitated in order to ensure the pursuit and achievement of these goals.

The study did not set out to gain a specific understanding about how masculinity affected men's experience of life with diabetes. While some of the findings may be interpreted or explained with reference to the performance of masculinity, the variation between, and within men's expression of masculine identity negates any definite conclusion about its impact on health. Rather, the study supports recent research which recommends that theorists attend to the possible expression of multiple masculinities (and variation in the expression of hegemonic masculinity).

## References

- Aikens, J., Wallander, J., Bell, D., & Cole, J. (1992). Daily Stress Variability, Learned Resourcefulness, Regimen Adherence, and Metabolic Control in Type 1 diabetes mellitus: Evaluation of a Path Model. *Journal of Consulting and Clinical Psychology, Vol. 60(1)*, pp: 113-118.
- Al-Khawaldeh, O., Al-Hassan, M., & Froelicher, E. (2012). Self-efficacy, self-management, and glycemic control in adults with type 2 diabetes mellitus. *Journal of Diabetes and Its Complications, Vol. 26*, pp: 10-16.
- Anderson, B. (2006). Families and chronic illness research: Targeting transitions and tools – Commentary on Trief et al. (2006). *Families, Systems & Health, Vol. 24(3)*, pp: 332-335.
- Anderson, J., Wiggins, S., Rajwani, R., Holbrook, A., Blue, C. & Ng, M. (1995). Living with a chronic illness: Chinese-Canadian and Euro-Canadian women with diabetes – Exploring factors that influence management. *Social Science and Medicine, Vol. 41(2)*, pp: 181-195.
- Arrington, M. (2005). 'She's right behind me all the way': An analysis of prostate cancer narratives and changes in family relationships. *The Journal of Family Communication, Vol. 5(2)*, pp: 141-162
- Arrington, M., Grant, C., & Venderford, M. (2005). Man to man, and side by side, they cope with prostate cancer: self-help and social support. *Journal of Psychosocial Oncology, Vol. 23(4)*, pp: 81-102
- Backett, K., & Davison, C. (1995). Lifecourse and Lifestyle: The social and cultural location of health behaviours\*. *Social Science & Medicine, Vol. 40(5)*, pp: 629-638.
- Bacon, C., Hu, F., Giovannucci, E., Glasser, D., Mittleman, M. & Rimm, E. (2002). Association of Type and Duration of Diabetes with Erectile Dysfunction in a Large Cohort of Men. *Diabetes Care, Vol. 25(8)*, pp: 1458–1463.



Bar-Lev, S. (2008). 'We are here to give you emotional support': Performing emotions in an online HIV/AIDS support group. *Qualitative Health Research*, Vol. 18(4), pp: 509-521.

Barak, A., Boniel-Nissim, M., & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behaviour*, Vol. 24, pp: 1867-1883.

Barker, K. (2008). Electronic support groups, patient-consumers, and medicalization: The case of contested illness. *Journal of Health and Social Behaviour*, Vol. 49(1), pp: 20-36.

Barrett, L., Robin, L., Pietromonaco, P., & Eyssell, K. (1998). Are women the 'more emotional' sex? Evidence from emotional experiences in social context. *Cognition and Emotion*, Vol. 12(4), pp: 555-578.

Bennett Johnson, S. (1992). Methodological Issues in Diabetes Research. Measuring Adherence. *Diabetes Care*, Vol. 15(11), pp: 1658-1667.

Bissonnette, J. (2008). Adherence: a concept analysis. *Journal of Advanced Nursing*, Vol. 63(6), pp: 634-643.

Boehmer, U. & Clark, J. (2001). Communication about prostate cancer between men and their wives. *The Journal of Family Practice*, Vol. 50(3), pp: 226-231.

Boehmer, U., & Clark, C. (2001). Married couples' perspectives on prostate cancer diagnosis and treatment decision-making. *Psycho-Oncology*, Vol. 10, pp: 147-155.

Borus, J., Blood, E., Volkening, L., Laffel, L., & Shrier, L. (2013). Momentary Assessment of Social Context and Glucose Monitoring Adherence in Adolescents with Type 1 Diabetes. *Journal of Adolescent Health*, Vol. 52, pp: 578-583.

Botoroff, J., Oliffe, J., Halpin, M., Phillips, M., McLean, G., & Mroz, L. (2008). Women and prostate cancer support groups: The gender connect? *Social Science &*

*Medicine*, Vol. 66, pp: 1217-1227.

Braun, V. (2000). Heterosexism in focus Group Research: Collusion and Challenge. *Feminism & Psychology*, Vol. 10, pp: 133-140.

Broom, A. (2004) Prostate Cancer and Masculinity in Australian Society: A Case of Stolen Identity? *International Journal of Men's Health*, Vol. 3(2), pp: 73-91.

Broom, A., Hand, K., & Tovey, P. (2009). The role of gender, environment and individual biography in shaping qualitative interview data. *International Journal of Social Research Methodology*, Vol. 12(1), pp: 51-65.

Broom, D. & Lenagh-Maguire, A. (2010). Gender configurations of diabetes: from rules to exceptions. *Journal of Gender Studies*, Vol. 19(2), pp: 195-209.

Broom, D., & Whittaker, A. (2004). Controlling diabetes, controlling diabetics: moral language in the management of diabetes type 2. *Social Science & Medicine*, Vol. 58, pp: 2371-2832.

Bryant, A. and Charmaz, K. Eds (2010) *The SAGE Handbook of Grounded Theory: Paperback Edition*. London: SAGE Publications Ltd

Caron-Flinterman, J. F., Broerse, J., Bunders, J. (2005). The experiential knowledge of patients: a new resource for biomedical research? *Social Science & Medicine*, Vol. 60, pp: 2575-2584.

Case, S., Jernigan, V., Gardner, A., Ritter, P., Heaney, C., Lorig, R. (2009). Content and Frequency of Writing on Diabetes Bulletin Boards: Does Race Make a Difference? *Journal of Medical Internet Research*, Vol. 11(2), doi: 10.2196/jmir.1153PMCID.

Casey, D., Murphy, K., Lawton, J., White, F., & Dineen, S. (2011). A longitudinal qualitative study examining the factors impacting on the ability of persons with T1DM to assimilate the Dose Adjustment for Normal Eating (DAFNE) principles

into daily living and how these factors change over time. *BMC Public Health*, Vol. 11, pp: 672-685

Centers for Disease Control and Prevention, (2011). *National Diabetes fact sheet: national estimates and general information on diabetes and prediabetes in the United States*. Retrieved from [www.cdc.gov](http://www.cdc.gov)

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, Vol. 5(2), pp: 168-197

Charmaz, K. (1990). 'Discovering' chronic illness using grounded theory. *Social Science and Medicine*, Vol. 30(11), pp: 1161-1172

Charmaz, K. (1991). *Good Days, Bad Days. The Self In Chronic Illness and Time*. New Jersey: Rutgers University Press.

Charmaz, K. (1994). Identity dilemmas of chronically ill men. *The Sociological Quarterly*, Vol. 35(2), pp: 269-288.

Charmaz, K. (2006). *Constructing Grounded Theory. A Practical Guide Through Qualitative Analysis*. London: Sage Publications.

Chatenoud, L. (2010). Immune therapy for type 1 diabetes mellitus – what is unique about anti-CD3 antibodies? *Nature Reviews Endocrinology*, Vol. 6, pp: 149-157.

Chen, A. (2012). Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Education and Counselling*, Vol. 87, pp: 250-257.

Chesler, M. (1987). *Professionals' views of the 'dangers' of self-help groups: Explicating a grounded theory approach*. (Centre for Research on Social Organization, Working Paper Series).

Ciechanowski, P.S., Katon, W.J., & Russo, J.E. (2000). Depression and diabetes:

Impact of depressive symptoms on adherence, function, and costs. *Archive Internal medicine*, 160, pp: 3278-3285.

Cleary, A. (2012). Suicidal action, emotional expression, and the performance of masculinities. *Social Science & Medicine*, Vol. 74(4), pp: 498-505.

Congalen, H., & Congalen, J. (2008). The impact of erectile-dysfunction on female partners: a qualitative investigation. *Sexual and relationship therapy*, Vol. 23(2), pp: 147-156.

Connell, R. W. (1995). *Masculinities. Second Edition*. Cambridge: Polity Press.

Corbin, J. & Strauss, A. (1990). Grounded Theory Research: Procedures, Canons, and Evaluative Criteria. *Qualitative Sociology*, Vol. 13(1), pp: 3-21.

Corbin, J. & Strauss, A. (2008). *Basics of Qualitative Research*. (3<sup>rd</sup> Ed.). London: Sage Publications.

Corbin, J., & Strauss, A. (1990). Grounded Theory Research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, Vol. 13(1), pp: 3-21.

Corona, G., Mannucci, E., Mansani, R., Petrone, L., Bartolini, M., Giommi, R., Forti, G. & Maggi, M. (2004). Organic, Relational and Psychological Factors in Erectile Dysfunction in Men with Diabetes Mellitus. *European Urology*, Vol. 46, pp: 222–228.

Courtenay, W., 2000. Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine*, Vol. 50, pp: 1385-1401.

Coyne, J. & Smith, D. (1991). Couples coping with a myocardial infarction: A contextual perspective on wives' distress. *Journal of Personality and Social Psychology*, Vol. 61(3), pp: 404-412.

Cranwell, J., & Seymour-Smith, S. (2012). Monitoring and normalising a lack of appetite and weight loss. A discursive analysis of an online support group for bariatric surgery. *Appetite*, pp: 873-881.

Dagenais, G., St-pierre, A., Gilbert, P., Lamarche, B., Després, J., Bernard, P., Bogaty, P. (2009). Comparison of prognosis for men with type 2 diabetes mellitus and men with cardiovascular disease. *Canadian Medical Association journal*, Vol. 180(1), pp: 40-47.

Davidson, K. & Meadows, R. (2009). Older Men's Health: the role of marital status and masculinities. In Gough, B. & Robertson, S. (Ed). *Men, Masculinities and Health. Critical Perspectives* pp: 124. Hampshire: Palgrave Macmillan.

Davison, K., Pennebaker, J., & Dickerson, S. (2000). Who Talks? The social psychology of illness support groups. *American Psychologist*, Vol. 55(2), pp: 205-217.

De Berardis, G., Franciosi, M., Belfiglio, M., Di Nardo, B., Greenfield, S., Kaplan, S., Pellegrini, F., Sacco, M., Tognoni, G., Valentini, M., & Nicolucci, A. Erectile dysfunction and quality of life in Type 2 diabetic patients. *Diabetes Care*, Vol. 25(2), pp: 284-291.

De Ridder, D., Schreurs, K., Kuijer, R. (2005). Is spousal support always helpful to patients with asthma or diabetes? A prospective study. *Psychology and Health*, Vol. 20(4), pp: 497-508.

Delamater, A.M., Jacobson, A.M., Anderson, B.J., Cox, D., Fisher, L., Lustman, P. et al. (2001). Psychosocial therapies in diabetes: Report of the psychosocial therapies working group. *Diabetes Care*, Vol. 24, pp: 1286-1292.

Dey, I. (1999). *Grounding Grounded Theory*. San Diego: Academic Press.

Diabetes UK, 2008. Diabetes. Beware the silent assassin. Retrieved from [http://www.diabetes.org.uk/Get\\_involved/Raising-awareness/Silent-Assassin-](http://www.diabetes.org.uk/Get_involved/Raising-awareness/Silent-Assassin-)

[campaign/](#) on 25/05/2011.

Dhindsa, S., Furlanetto, R., Vora, M., Ghanim, H., Chaudhuri, A., Dandona, P. (2011). Low estradiol concentrations in men with subnormal testosterone concentrations and type 2 diabetes. *Diabetes Care*, Vol. 34(8), pp: 1854-1859.

Driver, J., Chen, Y., Mathews, C. (2012). Comparative Genetics: Synergizing Human and NOD Mouse Studies for Identifying Genetic Causation of Type 1 Diabetes. *Rev Diabet Stud*. Vol. 9(4), pp: 169-187.

Ehlers, M. & Nepom, G. (2012). Immune-Directed Therapy for Type 1 Diabetes at the Clinical Level: The Immune Tolerance Network (ITN) Experience. *Rev Diabet Stud*. Vol 9(4), pp: 359-371.

Elliott, N. & Lazenbatt, A. (2004). How to recognise a 'quality' grounded theory research study. *Australian Journal of Advanced Nursing*, Vol. 22(3), pp: 48-52.

Enzlin, P., Mathieu, C., & Demyttenaere, K. (2002). Gender differences in the psychological adjustment to type 1 diabetes mellitus: an explorative study. *Patient Education and Counseling*, Vol. 48, pp: 139-145,

Eschenbeck, H., Kohlmann, C-W., & Lohaus, A. (2007). Gender differences in coping strategies in children and adolescents. *Journal of Individual Differences*, Vol. 28(1), pp: 18-26.

Fergus, K., Gray, R., & Fitch, M. (2002). Sexual dysfunction and the preservation of manhood: experiences of men with prostate cancer. *Journal of Health Psychology*, Vol. 7(3), pp: 303-316.

Ferrand, C., Perrin, C., & Nasarre, S. (2008). Motives for regular physical activity in women and men: a qualitative study in French adults with type 2 diabetes, belonging to a patients' association. *Health & Social Care in the Community*, Vol. 16(5), pp: 511-520.

Fisher, W., Rosen, R., Eardley, I., Sand, M., & Goldstein, I. (2005). Sexual experience of female partners of men with erectile dysfunction: The female experience of men's attitude to life events and sexuality (FEMALES) study. *The Journal of Sexual Medicine*, Vol. 2(5), pp: 675-684.

Frank, A. (1995). *The Wounded Storyteller*. Chicago: The University of Chicago Press.

Frost, J., & Massagli, M. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *Journal of Medical Internet Research*, Vol. 10(3), DOI: doi:10.2196/jmir.1053

Galdas, P., Cheater, F., & Marshall, P. (2005). Men and health help-seeking behaviour: literature review. *Journal of Advanced Nursing*, Vol, 49(6), pp: 616-623.

Gan, M., Albanese-O'Neill, A., & Heller, M. (2012). Type 1 diabetes: Current Concepts in Epidemiology, Psychopathology, Clinical Care, and Research. *Curr Probl Pediatr Adolesc Health Care*, Vol. 42, pp: 269-291.

Garfield, R. (2010). Male emotional intimacy: How therapeutic men's groups can enhance couples therapy. *Family Process*, Vol. 49, pp: 109-122.

Gilbert, E., Ussher, J., & Perz, J. (2010). Renegotiating sexuality and intimacy in the context of cancer: The experiences of carers. *Arch Sex Behav*, Vol. 39, pp: 998-1009.

Gillibrand, R. & Stevenson, J. (2006). The extended health belief model applied to the experience of diabetes in young people. *British Journal of Health Psychology*, Vol. 11, pp: 155-169.

Glaser, B., & Strauss, A. (1967) *The discovery of grounded theory*. Chicago: Aldine.

Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. New York: Prentice-Hall.

Gomersall, T., Madill, A., & Summers, L. (2012). Getting one's thoughts straight: A dialogical analysis of women's accounts of poorly controlled type 2 diabetes. *Psychology and Health*, Vol. 27(3), pp: 378-393.

Gomersall, T., Madill, A., & Summers, L. (2011). A metasynthesis of the self-management of Type 2 diabetes. *Qualitative Health Research*, Vol. 21(8), pp: 853-871.

Gooden, R., & Winefield, H. (2007). Breast and prostate cancer online discussion boards. A thematic analysis of gender differences and similarities. *Journal of Health Psychology*, Vol. 12(1), pp: 103-114.

Gough, B. (2007). 'Real men don't diet': An analysis of contemporary newspaper representations of men, food and health. *Social Science & Medicine*, Vol. 64, pp: 326-337.

Gough, B. & Robertson, S. (Eds.). (2010). *Men, Masculinities and Health. Critical Perspectives*. Hampshire: PALGRAVE MACMILLAN.

Gough, B., & Conner, M. (2006). Barriers to healthy eating amongst men: A qualitative analysis. *Social Science & Medicine*, Vol. 62, pp: 387-395.

Graham, K., Sutherland, R., Mannering, S., Zhao, Y., Chee, J., Krishnamurthy, B., Thomas, H., Lew, A., Kay, T. (2012). Pathogenic Mechanisms in Type 1 Diabetes: The Islet is Both Target and Driver of Disease. *Rev Diabet Stud.*, Vol. 9(4), pp: 148-168.

Greene, J., Choudry, N., Kilabuk, E., & Shrank, W. (2010). Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine*, Vol. 26(3), pp: 287-292.

Gregory, S. (2005). Living with chronic illness in the family setting. *Sociology of Health and Illness*, Vol. 27(3), pp: 372-392.



Griffith, L.S., Field, B.J., & Lustman, P.J. (1990). Life stress and social support in diabetes: Association with glycemic control. *International Journal of Psychiatric Medicine*, Vol. 20, pp: 365-372.

Grossmann, M. (2011). Low testosterone in men with type 2 diabetes: significance and treatment. *The Journal of Clinical Endocrinology and Metabolism*, Vol. 96(8), pp: 2341-2353.

Gullette, M. M. (1998). Midlife discourses in the twentieth century United States: An essay on the sexuality, ideology, and politics of middle-ageism. In Shweder, R. A. (Ed.) *Welcome to the Middle Age! (and Other Culture Fictions)*. Chicago: University of Chicago Press.

Harden, J., Schafenacker, A., Northouse, L., Mood, D., Smith, D., Pienta, K., Hussain, M., Baranowski, K. (2002). Couples' experiences with prostate cancer: Focus group research. *Oncology Nursing Forum*, Vol. 29(4), pp: 701-709.

Haynes, R. B., Yoa, X., Degani, A., Kripalani, S., Garg, A., & McDonald, H.P. (2005) Interventions to enhance medication adherence (Review). *Cochrane Database of Systematic Reviews*, Issue 4, pp: 1-77.

Heijman, M., De Ridder, D., & Bensing, J. (1999). Dissimilarity in patients' and spouses' representations of chronic illness: Exploration of relations to patient adaptation. *Psychology and Health*, Vol. 14, pp: 451-466.

Helgeson, V. S. & Novak, S. A. (2007) Illness Centrality and Well-Being Among Male and Female Early Adolescents with Diabetes. *Journal of Pediatric Psychology*, Vol. 32(3), pp: 260-272.

Henwood, K. & Pidgeon, N. (1992). Qualitative research and psychological theorizing. *British Journal of Psychology*, Vol. 83, pp: 97-111.

Hernandez, C. (1996). Integration: The experience of living with insulin dependent

(Type 1) Diabetes Mellitus. *Canadian Journal of Nursing Research*, Vol. 28(4), pp: 37-56.

Herod, A. (1993). Gender issues in the use of interviewing as a research tool. *Professional Geographer*, Vol. 45(3), pp: 305-317.

Hilliard, M., Wu, Y., Rausch, J., Dolan, L., & Hood, K. (2013). Predictors of Deteriorations in Diabetes Management and Control in Adolescents with Type 1 Diabetes. *Journal of Adolescent Health*, Vol. 52, pp: 28-34.

Hjelm, K. & Nambozi, G. (2008). Beliefs about health and illness: a comparison between Ugandan men and women living with Diabetes Mellitus. *International Nursing Review*, Vol. 55, pp: 434-441.

Hjelm, K., Bard, K., Nyberg, P. & Apelqvist, J. (2005). Beliefs about health and diabetes in men of different ethnic origin. *Journal of Advanced Nursing*, Vol. 50(1), pp: 47-59.

Hjelm, K., Nyberg, P., Isacson, Å., & Apelqvist, J. (1999) Beliefs about health and illness essential for self-care practice: a comparison of migrant Yugoslavian and Swedish diabetic females. *Journal of Advanced Nursing*, Vol. 30(5), pp: 1147-1159.

Hoffman-Goetz, L., Donelle, L., & Thomson, M. (2009). Clinical guidelines about diabetes and the accuracy of peer information in an unmoderated online health forum for retired persons. *Informatics for Health & Social Care*, Vol. 34(2), pp: 91-99.

Hollway, W. (1981). 'I just wanted to kill a woman.' Why? The ripper and male sexuality. *Feminist Review*, 9, pp: 33-40.

Hollway, W. (1984). Women's power in heterosexual sex. *Women's Studies Int. Forum*, Vol. 7(1), pp: 63-68.

Holmes, N. & Cooke, A. (2012). 1. Genetic Analysis of Type 1 Diabetes: Embryonic Stem Cells as New Tools to Unlock Biological Mechanisms in Type 1

Diabetes. *Rev Diabet Stud*, Vol. 9(4), pp: 137-147.

Hornsten, A., Lundman, B., Selstam, E., & Sandstrom, H. (2005). Patient satisfaction with diabetes care. *Journal of Advanced Nursing*, Vol. 51(6), pp: 609-617.

Huss, K. & Enskär, K. (2007). Adolescents' experience of living with diabetes. *Paediatric Nursing*, Vol. 19(3), pp: 29-31.

Husserl, E. (1970). *The Crisis of European Sciences and Transcendental Phenomenology*. Evanston, IL: Northwestern University Press.

Hyman, H., Cobb, W., Feldman, J., Hart, C., & Stember, C. (1954). *Interviewing in Social Research*. Chicago: University of Chicago Press.

Ingadottir, B. & Halldorsdottir, S. (2008). To Discipline a 'Dog': The essential structure of mastering diabetes. *Qualitative Health Research*, Vol. 18(5), pp: 606-619.

Jack, L., Toston, T., Jack, N., and Sims, M (2010). A Gender-Centred Ecological Framework Targeting Black Men Living With Diabetes: Integrating a 'Masculinity' Perspective in Diabetes Management and Education Research. *American Journal of Men's Health*, Vol. 4(1); pp: 7-15.

Joinson, A. (2003). *Understanding the psychology of Internet Behaviour: virtual worlds, real lives*. Basingstoke: Palgrave Macmillan.

Jones, H., Arver, S., Behre, H., Buvat, J., Meuleman, E., Moncada, I., Morales, A., Volterrani, M., Yellowlees, A., Howell, J., Channer, K., (2011). Testosterone replacement in hypogonadal men with type 2 diabetes and/or metabolic syndrome (the TIMES2 study). *Diabetes Care*, Vol. 34(4), pp: 828-837.

Jowett, A., Peel, E., & Shaw, R. (2011). Sex and Diabetes: a thematic analysis of gay and bisexual men's accounts. *Journal of Health Psychology*, DOI:

Kay, C., Davies, J., Gamsu, D. & Jarman, M. (2009). An Exploration of the experiences of young women living with type 1 diabetes. *Journal of Health Psychology*, Vol. 14(2), pp: 242-250.

Kirmayer, L. (1992). The body's insistence on meaning: metaphor as presentation and representation in illness experience. *Medical Anthropological Quarterly*, Vol. 6(4), pp: 323-346.

Koch, T., Kralik, D. & Taylor, J. (2000). Men living with diabetes: minimizing the intrusiveness of the disease. *Journal of Clinical Nursing*, Vol. 9, pp: 247-254.

Kraut, R., Olsen, J., Banaji, M., Bruckman, A., Cohen, J., & Couper, M. (2004). *American Psychologist*, Vol. 59(2), pp: 105-117.

Kyngäs, H., Duffy, M., & Kroll, T. (2000). Conceptual analysis of compliance. *Journal of Clinical Nursing*, Vol. 9, pp: 5-12.

Lawson, V., Lyne, P., Harvey, J., & Bundy, C. (2005). Understanding why people with Type 1 diabetes do not attend for specialist advice: A qualitative analysis of the views of people with insulin-dependent diabetes who do not attend diabetes clinics. *Journal of Health Psychology*, Vol. 10(3), pp: 400-423.

Lawton, J. (2002). Colonising the future: temporal perceptions and health-relevant behaviours across the adult lifecourse. *Sociology of Health & Illness*, Vol. 24(6), pp: 714-733.

Lawton, J., Peel, E., Parry, O., & Douglas, M. (2008) Shifting Accountability: A longitudinal qualitative study of diabetes causation accounts. *Social Science & Medicine*, Vol. 67, pp: 47-56.

Lawton, J., Rankin, D., Peel, E., & Douglas, M. (2009). Patients' perceptions and experiences of transitions in diabetes care: a longitudinal qualitative study. *Health*

*Expectations*, Vol. 12, pp: 138-148.

Lee, C. & Owens, R. (2002). *The Psychology of Men's Health*. Philadelphia: Open University Press.

Leonard, J. (2004). Diabetes and men's health issues. *Diabetes Spectrum*, Vol. 17(4), pp: 206-208.

Lieberman, M. (2008). Gender and online cancer support groups: issues facing male cancer patients. *Journal of Cancer Education*, 23(2), 167-171.

Luftey, K. & Wishner, W. (1999). Beyond 'Compliance' is 'Adherence'. Improving the prospect of diabetes care. *Diabetes Care*, Vol. 22(4), pp: 635-639.

Lunt, H. (1996). Women and diabetes. *Diabetic Medicine*, Vol. 13(12), pp: 1009-1016.

Mahalik, J. R., Burns, S. M., & Syzdek, M. (2007). Masculinity and perceived normative health behaviors as predictors of men's health behaviors. *Social Science and Medicine*, Vol. 64, pp: 2201-2209.

Mahalik, J., Levi-Minzi, M., & Walker, G. (2007). Masculinity and health behaviours in Australian men. *Psychology of Men and Masculinity*, Vol. 8(4), pp: 240-249.

Matud, M. (2004). Gender differences in stress and coping styles. *Personality and Individual Differences*, Vol. 37, pp: 1401-1415.

McConatha, J., Lightner, E., & Deaner, S. (1994). Culture, age, and gender as variables in the expression of emotions. *Journal of Social Behaviour and Personality*, Vol. 9(3), pp: 481-488.

McGuire, B. & Walsh, J.C. (2006). Diabetes self-management: Facilitating behaviour change. *Diabeteswise*, Vol. 3(1), pp: 2-6.

McDaid, D. & Park, A. (2011). BUPA Health Pulse 2010. Online Health: Untangling the web. Retrieved from [www.bupa.com/healthpulse](http://www.bupa.com/healthpulse)

Miller, D. & Brown, L. (2005). Marital Interactions in the Process of Dietary Change for Type 2 diabetes. *J Nutr Educ Behav*, Vol. 37, pp: 226-234.

Mo, P., & Coulson, N. (2010). Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of 'lurkers' and 'posters'. *Computers in Human Behaviour*, Vol. 26, pp: 1183-1193.

Morrison, V. & Bennett, P. (2006) *An Introduction to Health Psychology*. Essex: Pearson Education Limited.

Mróz, L., Chapman, G., Oliffe, J., & Bottorff, J. (2011). Gender relations, prostate cancer and diet: Re-inscribing hetero-normative food practices. *Social Science and Medicine*, Vol. 72, pp: 1499-1506.

Mulveen, R., & Hepworth, J. (2006). An interpretative phenomenological analysis of participation in a pro-anorexia internet site and its relationship with disordered eating. *Journal of Health Psychology*, Vol. 11(2), pp: 283-296.

Munir, F., Pryce, J., Haslam, C., Leka, S., & Griffiths, A. (2006). Gender differences in managing chronic illness at work: Exploring predictors for disclosure. *Journal of Vocational Rehabilitation*, Vol. 25, pp: 173-180.

Newton, P., Scambler, S., & Asimakopoulou, K. (2011). Marrying contradictions: Healthcare professionals perceptions of empowerment in the care of people with Type 2 diabetes. *Patient Education and Counselling*, Vol. 85, pp: 326-329.

Noone, J. & Stephens, C. (2008). Men, masculine identities and health care utilisation. *Sociology of Health and Illness*, Vol. 30(5), pp: 711-725.

Oftedal, B., Karlsen, B. & Bru, E., (2010). Perceived support from healthcare

practitioners among adults with type 2 diabetes. *Journal of Advanced Nursing*, Vol. 66(7), pp: 1500-1509.

Öhman, M. & Söderberg, S. (2004). The experiences of close relatives living with a person with a serious chronic illness. *Qualitative Health Research*, Vol. 14, pp: 396-410.

Oliffe, J. (2005). Constructions of masculinity following prostatectomy-induced impotence. *Social Science & Medicine*, Vol. 60(10), pp: 2240-2259.

Oliffe, J. & Mróz, L. (2005). Men interviewing men about health and illness: ten lessons learned. *Jmhg*, Vol. 2(2), pp: 257-260.

Parry, O., Peel, E., Douglas, M., & Lawton, J. (2006). Issues of cause and control in patients accounts of Type 2 diabetes. *Health Education Research. Theory and Practice*, Vol. 21(1), pp: 97-107.

Paterson, B. & Thorne, S. (2000). Development evolution of expertise in diabetes self-management. *Clinical Nursing Research*, Vol. 9(4), pp: 402-419.

Paterson, B. & Thorne, S. (2000). Expert decision making in relation to unanticipated blood glucose levels. *Research in Nursing and Health*, Vol. 23(2), pp: 147-157.

Paterson, B., Thorne, S., Crawford, J., & Tarko, M. (1999). Living with diabetes as a transformational experience. *Qualitative Health Research*, Vol. 9(6), pp: 786-802.

Peel, E., Parry, O., Douglas, M., & Lawton, J. (2006). 'It's No Skin off My Nose': Why People take Part in Qualitative Research. *Qualitative Health Research*, Vol. 16(10), pp: 1335-1349.

Peel, E., Parry, O., Douglas, M., & Lawton, J. (2005). Taking the Biscuit? A discursive approach to managing diet in Type 2 diabetes. *Journal of Health Psychology*, Vol. 10(6), pp: 779-791.

Penson, D., & Wessells, W. () Erectile dysfunction in diabetic patients. *Diabetes Spectrum, Vol. 17(4)*, pp: 225-232.

Peyrot, M., McMurray, J. & Hedges, R. (1988) Marital adjustment to adult diabetes. Interpersonal congruence and spouse satisfaction. *Journal of Marriage and the Family, Vol. 50*, pp: 363-376.

Peyrot, M., Rubin, T., Lauritzen, T., Snoek, F., Matthews, D., & Skovlund, S.E. (2005). Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes & Needs (DAWN) Study. *Diabetic Medicine, Vol. 22*, pp: 1379-1385.

Pidgeon, N., & Henwood, K. (1997). Using Grounded Theory in Psychological Research. In Hayes, N. (Eds.), *Doing Qualitative Analysis in Psychology* (pp: 245-273). Hove: Psychology Press.

Playle, J.F. & Keeley, P. (1998). Non-compliance and professional power. *Journal of Advanced Nursing, Vol. 27*, pp: 304-311.

Polce-Lynch, M., Myers, B., Kilmartin, C., Forssmann-Flack, R., & Kliewer, W. (1998). Gender and age patterns in emotional expression, body image, and self-esteem: A qualitative analysis. *Sex Roles, Vol. 38*, pp: 1025-1048.

Potter, J., & Hepburn, A. (2005). Qualitative interviews in psychology: problems and possibilities. *Qualitative Research in Psychology, Vol. 2*, pp: 281-307.

Potts, A. (2000). 'The Essence of the Hard on': Hegemonic masculinity and the cultural construction of 'Erectile Dysfunction'. *Men and Masculinities, Vol. 3(1)*, pp: 85-103.

Potts, A. (2001). The Man with Two Brains: hegemonic masculine subjectivity and the discourse construction of the unreasonable penis-self. *Journal of Gender Studies, Vol. 10(2)*, pp: 145-156.



Potts, A., Grace, V., Vares, T., & Gavey, N. (2006). 'Sex for life'? Men's counter-stories on 'erectile dysfunction', male sexuality and ageing. *Sociology of Health and Illness*, Vol. 28(3), pp: 306-329.

Preis, S., Hwang, S., Coady, S., Pencina, M., D'agostino, R., Savage, P., Levy, D., Fox, C. (2009). Trends in all-cause and cardiovascular disease mortality among women and men with and without diabetes mellitus in the Framingham Heart Study, 1950 to 2005. *Circulation*, Vol. 119(13), pp: 1728-1735.

Prilleltensky, I. & Prilleltensky, O. (2003). Towards a Critical Health Psychology Practice. *Journal of Health Psychology*, Vol. 8(2), pp: 197-210.

Rasmussen, B., O'Connell, B., Dunning, P., & Cox., H. (2007). Young women with Type 1 diabetes management of turning points and transitions. *Qualitative Health Research*, Vol. 17(3), pp: 300-310.

Ravert, R., Hancock, M., & Ingersoll, G. (2004). Online forum messages posted by adolescents with type 1 diabetes. *The Diabetes Educator*, Vol. 30(5), pp: 827-834.

Rees, J., O'Boyle, C., & MacDonagh, R. (2001). Quality of life: impact of chronic illness on the partner. *Journal of the Royal Society of Medicine*, Vol. 94, pp: 563-555.

Robertson, S. (2007). *Understanding Men and Health. Masculinities, Identity and Well-being*. Berkshire: Open University Press.

Robichaud, M., Dugas, M., & Conway, M. (2003). Gender differences in worry and associated cognitive-behavioral variables. *Anxiety Disorders*, Vol. 17, pp: 501-516.

Rodgers, S.. & Chen, Q. (2005). Internet community group participation: Psychosocial benefits for women with breast cancer. *Journal of Computer-Mediated Communication*, Vol. 10(4), article 5 URL: <http://jcmc.indiana.edu/vol10/issue4/rodgers.html>

Rodham, K., & Gavin, J. (2006). The ethics of using the internet to collect qualitative data. *Research Ethics Review*, Vol. 2(3), pp: 92-97.

Sackett, D. L. (1976) Introduction and magnitude of compliance and noncompliance. In: *Compliance with Therapeutic regimens* (Sackett D.L. & Haynes R.B., eds), The Johns Hopkins University Press. Baltimore: MD, pp: 1-25.

Sallaeg, K. & Chapman, G. (2008). Masculinity and food ideals of men who live alone. *Appetite*, Vol. 51, pp: 120-128.

Salonstall, R. (1993). Healthy bodies, social bodies: Men's and women's concepts and practices of health in everyday life. *Social Science & Medicine*, Vol. 36(1), pp: 7-14.

Schilling, L. (2002). The concept of self-management of type 1 diabetes in children and adolescents: an evolutionary concept analysis. *Nursing Theory and Concept Development of Analysis*, Vol. 37(1), pp: 87-99.

Schmitt, G., & Neubeck, G. (1985). Diabetes, sexuality, and family-functioning. *Family Relations*, Vol. 34(1), pp: 109-113.

Schur, H., Gamsu, D., & Barley, V. (1999). The young person's perspective on living and coping with diabetes. *Journal of Health Psychology*, Vol. 4(2), pp: 223-236.

Seale, C., Ziebland, S., & Charteris-Black, J. (2006). Gender, cancer experience and internet use: A comparative keyword analysis of interviews and online cancer support groups. *Social Science & Medicine*, Vol. 62, pp: 2577-2590.

Seymour-Smith, S. (2008). 'Blokes don't like that sort of thing'. Men's negotiations of a 'troubled' self-help group identity. *Journal of Health Psychology*, Vol. 13(6), pp: 785-797.

Seymour-Smith, S. (in press). A reconsideration of the gendered mechanisms of

support in online interactions about testicular implants: a discursive approach. *Psychology and Health*.

Seymour-Smith, S. & Wetherell, M. (2006) 'What he hasn't told you...': Investigating the micro-politics of gendered support in heterosexual couples' co-constructed accounts of illness. *Feminism & Psychology*, Vol. 16(1), pp: 105-127.

Shapiro, J. (2012). Islet Transplantation in Type 1 Diabetes: Ongoing Challenges, Refined Procedures, and Long-Term Outcome. *Rev Diabet Stud*, Vol. 9(4), pp: 385-406.

Sherbourne, C.D., Hays, R.D., Ordway, L., DiMatteo, M.R., & Kravitz, R. L. (1992). Antecedents of adherence to medical recommendations: Results from the Medical Outcomes Study. *Journal of Behavioural medicine*, Vol. 15(5), pp; 321-332.

Simpson, P., & Kroch, L. (2004). Gender Differences: Emotional expression and feelings of personal inauthenticity. *Journal of Applied Psychology*, Vol. 89(4), pp: 715-721.

Smith, B., & Sparkes, A. (2004). Men, sport, and spinal cord injury: an analysis of metaphors and narrative types. *Disability & Society*, Vol. 19(6), pp: 613-626.

Smith, J., Braunack-Mayer, A., & Wittert, G. (2006). What do we know about men's help-seeking and health service use? *MJA*, Vol. 184(2), pp: 81-83.

Soloway, C., Soloway, M., Kim, S., & Kava, B. (2005). Sexual, psychological and dyadic qualities of the prostate cancer 'couple'. *BJU International*, Vol. 95, pp: 780-785.

Sparaud-Lundin, C., Öhrn, I., & Danielson, E. (2010). Redefining relationships and identity in young adults with type 1 diabetes. *Journal of Advanced Nursing*, Vol. 66(1), pp: 128-138.

Speer, S. (2001). Reconsidering the Concept of Hegemonic Masculinity: Discursive

psychology, conversation analysis and participants' orientations. *Feminism & Psychology*, Vol. 11(1), pp: 107-135.

Stainton Rogers, W. (1996). Critical Approaches to Health Psychology. *Journal of Health Psychology*, Vol. 1(1), pp: 65-77.

Stam, H. (2000). Theorizing Health and Illness: functionalism; subjectivity; and reflexivity. *Journal of Health Psychology*, Vol. 5(3), pp: 273-283.

Stephens, M., Rook, K., Franks, M., Khan, C., & Iida, M. (2010). Spouses use of social control to improve diabetic patients' dietary adherence. *Families, Systems & Health*, Vol. 28(3), pp: 199-208.

Suler, J. The Online Disinhibition Effect. *CyberPsychology & Behaviour*, Vol. 7(3), pp: 321-326.

Sullivan, C. (2003). Gendered Cybersupport: A thematic analysis of two online cancer support groups. *Journal of Health Psychology*, Vol. 8(1), pp: 83-103.

Taylor, S. (1995). *Health Psychology*, 3<sup>rd</sup> Eds. New York: McGraw Hill.

Taylor, B. & de Vocht, H. (2011). Interviewing Separately or as Couples? Considerations of Authenticity of Method. *Qualitative Health Research*, Vol. 21, pp: 1576-1587.

Thompson, S. & Pitts, J. (1992). In sickness and in health: chronic illness, marriage and spousal caregiving. In: S. Spacapan and S. Oskamp (Eds.), *Helping and Being Helped: Naturalistic Studies*, pp: 115-151. Newbury Park: Sage Publications.

Trief, P., Ploutz-Snyder, R., & Britton, K. (2004). The relationship between marital quality and adherence to the diabetes care regimen. *Annals of Behavioral Medicine*, Vol. 27(3), pp: 148-154.

Trief, P., Sandberg, J., Greenberg, R., Graff, K., Castronova, N., Yoon, M., &

Weinstock, R. (2003). Describing Support: A qualitative study of couples living with diabetes.

VanDevanter, N., Thacker, A., Bass, G., & Arnold, M. (1999). Heterosexual couples confronting the challenges of HIV infection. *AIDS Care*, Vol. 11(2), pp: 181-193.

Walker, H. (Eds.) *Advances in Group Processes* pp: 89-113. Greenwich, CT: JAI Press.

Wannamethee, G., Shaper, G., and Walker, M. (2005). Overweight and obesity and weight change in middle aged men: impact on cardiovascular disease and diabetes. *Journal of epidemiology and community health*, Vol.59(2), pp.134-9.

Watts, S., O'Hara, L., & Trigg, R. (2010). Living with Type 1 diabetes: A by-person qualitative exploration. *Psychology and Health*, Vol. 25(4), pp: 491-506.

Weardon, A., Tarrier, N., & Davies, Rob. (2000). Partners' expressed emotion and the control and management of Type 1 diabetes in adults. *Journal of Psychosomatic Research*, Vol. 49, pp: 125-130.

Weed, M. (2009). Research quality considerations for grounded theory research in sport & exercise psychology. *Psychology of Sport and Exercise*, Vol. 10, pp: 502-510.

Weijman, I., Ros, W., Rutten, G., Schaufeli, W., Schabracq, M., Winnubst, J. (2005). The role of work-related and personal factors in diabetes self-management. *Patient Education and Counselling*, Vol. 59, pp: 87-96.

Wetherell, M. & Edley, N. (1999). Negotiating hegemonic masculinity: Imaginary positions and psycho-discursive practices. *Feminism & Psychology*, Vol. 9(3), pp: 335-356.

Williams, C. (2000) Doing health, doing gender: teenagers, diabetes and asthma. *Social Science & Medicine*, Vol. 50, pp: 387-396.

Willig, C. (2001). *Introducing Qualitative Research in Psychology. Adventures in theory and method*. New York: Two Penn Plaza.

Wilson, P., Kendall, S., & Brooks, P. (2005). Nurses' responses to expert patients: The rhetoric and reality of self-management in long term conditions: A grounded theory study. *International Journal of Nursing Studies*, Vol. 43, pp: 803-818.

Winkley, K., Landau, S., Eisler, I. & Ismail, K. (2006). Psychological interventions to improve glycaemic control in patients with type 1 diabetes: systematic review and meta-analysis of randomised controlled trials. *British Medical Journal*. Doi: 10.1136/bmj.38874.652569.55 (published 27 June 2006).

World Health Organization (2013). Diabetse Fact Sheet No. 312. Retrieved 27/08/13 <http://www.who.int/mediacentre/factsheets/fs312/en/>

World Health Organization (2003). *Adherence to long-term Therapies: Evidence for Action* (Sabate E., ed.), World Health Organisation, Geneva, p. 196.

Zakowski, S., Harris, C., Krueger, N., Laubmeier, K., Garrett, S., Flanigan, R., & Johnson, P. (2003). Social barriers to emotional expression and their relations to distress in male and female cancer patients. *British Journal of Healthy Psychology*, Vol. 8, pp: 271-286.

Zoffman, V. & Lauritzen, T. Guided self-determination improves life skills with Type 1 diabetes and A1C in randomized controlled trial. *Patient Education and Counselling*, Vol. 64, pp: 78-86.

Zrebiec, J., & Jacobson, A. (2001). What attracts patients with diabetes to an internet support group? A 21-month longitudinal website study. *Diabetes Medicine*, Vol. 18, pp: 154-158.

## **List of Appendices**

**Appendix A:** Interview Schedule (Chapter IV)

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## **Appendix A: Interview Schedule (Chapter IV)**

### **Type 1 Diabetes in Men: A Qualitative Study of Life with a Chronic Illness**

#### **Interview Schedule (Chapter IV)**

The interview shall be very informal and it is hoped that the participant shall have the opportunity to discuss any topics that are of particular interest to him. As such, the following interview schedule is only a guide to the possible areas that will be covered.

#### **DIAGNOSIS**

Can you start by telling me a little about what life was like before you were diagnosed with diabetes?

^ Health-wise, socially, professionally.

Can you tell me about when you were first diagnosed with diabetes?

- How did you first discover that there was a problem?
- When did you go to the doctors?

Can you remember how you felt when you were first told you had diabetes?

- Had you known much about diabetes previously?
- Had you known anyone else who suffered from diabetes?

How did your family and friends react to your diagnosis?

- how did your work colleagues and employer react?

#### **IMPACT OF ILLNESS**



Did your diagnosis change your life in any way?

- ⤴ Socially, physically, emotionally, work, education etc.?

In what ways did it affect your quality of life?

- Did it stop you from doing things that you used to do before?
- Did your outlook on life change?

How do you integrate diabetes into your life?

- ⤴ Eating, sleeping, exercise etc.
- ⤴ Is diabetes easy or difficult to manage?
- ⤴ How effective is medication alone at managing diabetes?
- ⤴ How is your daily routine different to that of someone without diabetes?

Can you remember any particular time when having diabetes stopped you doing what you wanted to do? How did this make you feel?

Have you suffered from complications as a result of your illness?

Do people treat you differently because you have diabetes?

Are there ways diabetes has benefited your life?

### **FEELINGS TOWARDS DIABETES**

Can you describe to me what it feels like to live with diabetes?

- Is it something you are always aware of?
- How do you view your quality of life?
- Would you say that you suffer from diabetes?
- Do you view it as a disability?

- Do you see it as a serious illness?
- Do you have any fears about your illness?

How have these feelings changed since you were diagnosed?

Do you think that non-diabetics understand the way you feel?

How do your family and friends respond to your condition?

- ⤴ How does your illness affect them?
- ⤴ Do they worry?

Some people describe living with Diabetes as a job that they may not like, but they have to do, would you agree with this?

Are there rewards for doing this job?

Have you ever felt like quitting the diabetes care regimen?

- ⤴ How did you feel?
- ⤴ What did you do?

There's a common stereotype that men try to portray a very sturdy persona, and often reject or deny illness in order to protect their masculinity. Would you agree with this?

-Have you had any experience of this as a diabetic?

### **PAST, PRESENT AND FUTURE**

If you could go back to the day you were diagnosed, would you change any of the things you have done since?

Would you say you are currently in control of your illness?

-Do you control diabetes or does diabetes control you?

How do you view your future with diabetes?

Do you ever wish for a life without diabetes?

What advice would you give to somebody recently diagnosed with diabetes?

## **Appendix B: Interview Schedule (Chapter VI)**

### **Type 1 Diabetes in Men: A Qualitative Study of Life with a Chronic Illness**

#### **Interview Schedule**

The interview shall be very informal and it is hoped that the participants shall have the opportunity to discuss any topics that are of particular interest to them. All participants will have received the information sheet prior to participation in the interview. Participants will also have completed a short questionnaire providing information regarding how long they have been in a relationship together, number of children they have, employment information, length of time since diagnosis with diabetes, and the presence (if any) of diabetes-related complications. Each interview shall be individually tailored in response to the information received from the questionnaires. As such, the following interview schedule is only a guide to the possible areas that will be covered.

#### **BACKGROUND INFO (QUESTIONS DIRECTED TO NON-DIABETIC PARTNER)**

Prior to meeting “John” (insert partner’s name), had you known much about diabetes and in particular, Type 1 diabetes?

Can you recall how you reacted when you found out about his condition?  
Did you have any concerns about it?

Did you ever think about how diabetes would impact on your future?

#### **BACKGROUND INFO (QUESTIONS DIRECTED TO DIABETIC**

### **PARTNER)**

Were you apprehensive about telling Julie (insert female partner's name) about your diabetes?

### **BACKGROUND INFO (QUESTIONS DIRECTED TO BOTH)**

Can you tell me about what kind of presence diabetes held in the early days of your relationship?

Back then, how were you both, health-wise? Did you (diabetic partner) suffer from any diabetes-related complications?

What about now, does diabetes hold the same status in your lives as it did back then, or have things changed?

### **LIVING WITH DIABETES TODAY (QUESTIONS DIRECTED TO DIABETIC PARTNER)**

You've now been diagnosed with diabetes for X number of years, in what way (if at all) has your attitude to diabetes changed over the years?

- ^ What has brought about this change?
- ^ How do you think this change in attitude to diabetes has been received by your partner?

What do you see your role as in the management of the diabetes?

What kind of role does your partner play in the management of your diabetes?

Do you think that Julie understands what life is like for you as a diabetic?

**LIVING WITH DIABETES TODAY (QUESTIONS DIRECTED TO  
NON-DIABETIC PARTNER)**

Over the course of your relationship, how would you describe your role in the management of “John’s” diabetes?

Have there ever been times when you have had to help John during an episode of severe hypoglycaemia or hyperglycaemia?

- ♣ Can you tell me about that?
- ♣ How did it make you feel to see your partner in that state?

As someone who lives with the presence of diabetes in your family everyday, what are your feelings towards it?

- ♣ Does it ever cause you worry?
- ♣ Do you ever wish for John to be cured?

**LIVING WITH DIABETES TODAY (QUESTIONS DIRECTED TO  
BOTH PARTNERS)**

Do you talk to each other about your feelings towards diabetes?

Do you see diabetes as something that is only experienced by the individual diabetic, or does it have a wider reach?

What are your feelings towards the future with diabetes?

## Appendix C: Background Questionnaire (Chapter VI)

### Type 1 Diabetes in Men: A Qualitative Study of Life with a Chronic Illness

#### Background Questionnaire

♣ Ages: Male \_\_\_\_\_ Female \_\_\_\_\_

♣ Number of years diagnosed with Type 1 diabetes: \_\_\_\_\_

♣ Number of years in a relationship together: \_\_\_\_\_

♣ Number of children: \_\_\_\_\_

♣ Please provide brief employment details:

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♣ Please provide details of any diabetes-related complications (i.e. type of complication; when did it first appear):

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♣ Please give details of diabetes treatment regimen and how long you have been using this treatment (i.e. multiple daily injections or insulin pump):

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⤴ Please give your most recent HBA1c reading (optional): \_\_\_\_\_



## **Appendix D: Debrief Sheet (Chapters IV and VI)**

### **Type 1 Diabetes in Men: A Qualitative Study of Life with a Chronic Illness**

#### **Debrief Sheet**

Thank you for your participation in this study.

The purpose of this project is to explore what living with Type 1 diabetes is like. The information you have provided may be quoted in a subsequent report, and in any subsequent publication(s). Your data will be de-identified by the use of pseudonyms and by the re-naming of any other identifying information (place, age, and any other recognisable personal details).

We remind you that you may withdraw your data from the study following completion of the interview, without providing any reason. If you do not want your data to be included in the research, please contact the researcher at [Lesley.ohara@ntu.ac.uk](mailto:Lesley.ohara@ntu.ac.uk), or at the contact address provided below. Please provide the pseudonym you have been allocated, as this will be used to identify your data and withdraw it from the study.

Once again, we would like to thank you for participating in this study. We are aware that some of the items discussed are of a sensitive nature. Should you require any advice or counselling services in relation to these items, please see the support details provided below.

If you have any further queries regarding this study, please contact the researcher, Lesley O'Hara at [Lesley.ohara@ntu.ac.uk](mailto:Lesley.ohara@ntu.ac.uk) or at the contact address below. Alternatively you may contact the research supervisor, Prof. Brendan Gough at the address below.

✧ **Diabetes UK:** (020) 7424100; <http://www.diabetes.org.uk>

✧ **American Diabetes Association:** <http://www.diabetes.org/home.jsp>

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## **Appendix E: Information Sheet (Chapter IV)**

### **Type 1 Diabetes in Men: A Grounded Theory Study of Life with a Chronic Illness**

#### **Information Sheet**

You are invited to take part in a study about men with Type 1 diabetes. The purpose of this study is to describe what life is like for men with Type 1 diabetes, specifically, how diabetes has evolved since the point of diagnosis, and how life has changed over time.

The project is entitled Type 1 Diabetes in Men: A Qualitative Study of Life with a Chronic Illness. The researcher is Lesley O'Hara, a PhD student from the Psychology Division of Nottingham Trent University (NTU). The researcher also has Type 1 diabetes. The research is being supervised by Prof. Brendan Gough (contact details are supplied below), Dr. Simon Watts and Dr. Sarah Seymour-Smith of the Psychology Division at NTU.

Information will be obtained through a series of one-to-one interviews, conducted by the researcher. The interviews shall be recorded using audio-recording equipment and will last between 30 minutes and 2 hours. These interviews will take place in a room at Nottingham Trent University, or in your own home should you prefer. Any travel expenses incurred by taking part shall be paid by the researcher.

The interview schedule provides a general outline of the topics that will be discussed. You may, should you wish, view the interview schedule before the start of the interview.

You may freely decline to answer any questions which you deem to be too

sensitive and you are free to discuss any items which are not mentioned in the interview schedule. Upon completion of the interview you will have the opportunity to ask any questions you may have about the research. You are also free to contact the researcher at any stage after the interview to discuss any aspect of the study. Contact details for support groups are provided at the end of this document.

Following the interview, the recording will be transcribed word-for-word. In order to protect your confidentiality, your data will be de-identified by the use of pseudonyms, and by the re-naming of any other identifying information (e.g. place, and any other recognisable personal details). Data will be stored on a password protected lap-top, the researcher is the only person with access to the password. The data will be viewed by the researcher, research-supervisors and examiners, and may also be viewed by academics if it appears in future publications, presentations and teaching.

You may withdraw from the interview at anytime, without providing a reason. You may withdraw your data from the study following completion of the interview, without providing a reason, by contacting the researcher directly. Please note that word-for-word extracts from your interview may be used in research reports and future publications. They may also be used for conferences and teaching. If you do not want your data to be included in the research you can contact the researcher directly (details provided below).

If you are interested in taking part in this study, or have any questions relating to the research, please contact Lesley O'Hara at the contact details provided below.

Thank you.

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Support details:

- ⤴ **Diabetes UK:** (020) 7424100; <http://www.diabetes.org.uk>
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## **Appendix F: Information Sheet (Chapter VI)**

### **Type 1 Diabetes in Men: A Grounded Theory Study of Life with a Chronic Illness**

#### **Information Sheet**

You are invited to take part in a study about living with Type 1 diabetes. The purpose of the study is to describe what life is like for men with Type 1 diabetes and their partners. I am interested in how the couple have adjusted to life with diabetes and how their relationship with diabetes has changed over time.

The project is entitled Type 1 Diabetes in Men: A Qualitative Study of Life with a Chronic Illness. The researcher is Lesley O'Hara, a PhD student from the Psychology Division of Nottingham Trent University (NTU). The researcher also has Type 1 diabetes. The research is being supervised by Prof. Brendan Gough (contact details are supplied below), Dr. Simon Watts and Dr. Sarah Seymour-Smith of the Psychology Department at NTU.

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If you are interested in taking part in this study, or have any questions relating to the research, please contact Lesley O'Hara at the contact details provided below.

Thank you.

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## **Appendix G: Declaration of Informed Consent (Chapters IV and VI)**

### **Type 1 Diabetes in Men: A Qualitative Study of Life with a Chronic Illness**

#### **Declaration of Informed Consent**

**Please read and confirm your consent to being interviewed for this project by ticking the appropriate box(es) and signing and dating this form.**

1. I confirm that the purpose of the project has been explained to me, that I have been given information about it in writing, and that I have had the opportunity to ask questions about the research
  
2. I have been informed of, and reserve my right to withdraw myself or my data from the study, without penalty of any kind and without providing any reason. I am aware that to do so I can ring or email the researcher.
  
3. I understand that all data collected from my participation will be de-identified by use of pseudonym, and by the re-wording of any other identifying information
  
4. I have been advised that my data may be used in a subsequent report, and in any subsequent publication(s)
  
5. I am aware that all anonymous data may be retained by the researcher

and used in future studies, publications, conferences and teaching

6. I have been informed that any concerns about the study may be referred to the researcher, Lesley O'Hara, or the research supervisor, Prof. Brendan Gough, at Nottingham Trent University (contact details below)

7. I agree to take part in this project.

Signed:

\_\_\_\_\_ Participant

\_\_\_\_\_ Print Name

\_\_\_\_\_ Investigator

\_\_\_\_\_ Date

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